# State of Delaware Division of Public Health Family Health Section

Maternal and Child Health Title V Five Year Needs Assessment July 7, 2005

# Table of Contents

1.	Process for conducting the Needs Assessment	1
	A. Methodology	1
	B. CSGCN Needs Assessment Process	1
	C. Early Intervention Needs Assessment	2
	D. MCH Steering Committee Needs Assessment Process	3
	E. Strengths and Weaknesses of the Needs Assessment	6
2.	Needs Assessments Partnership Building and Collaboration	7
3.	Assessment of the Needs of the Maternal and Child Health Population Groups	15
	A. Overview of Delaware Demographics	16
	B. Population	18
	C. Geographic Disparities	21
	D. Racial and Health Disparities	22
	E. Poverty	28
	F. Medicaid	31
	G. Housing and Homeless	33
4.	Pregnant Women, Mothers and Infants	34
	A. Major Health Issues, Gaps, Disparities	34
	B. Program Capacity by Pyramid Levels	46
5.	Children and Adolescents	59
	A. Major Health Issues, Gaps, Disparities	59
	B. Program Capacity by Pyramid Levels	82
6.	Children with Special Health Care Needs	91
	A. Major Health Issues, Gaps, Disparities	91
	B. Program Capacity by Pyramid Levels	92
7.	Linkages to Promote Provision of Services and Referrals	98
8.	Infrastructure-Building Services	99
0.	A. Total Maternal Child Health Population	99
	B. Pregnant Women, Mothers and Infants	104
	C. Children and Adolescents	110
	D. Children with Special Health Care Needs	111
	E. Major Providers of Health and Health Related Services	111
	E. Major Froviders of Health and Health Related Services	119
9.	Selection of State Priority Needs.	121
	A. Determination of Delaware's Priorities	121
	B. Delaware's Priorities related to Pyramid of Services	121
10.	Needs Assessment Summary	124

# Table of Contents (continued)

11.	Ke	y Reports and Other Resources	12'
	A.	Reports	12'
		Other References.	12

#### **B.** Five Year Needs Assessment

# 1. Process for Conducting the Needs Assessment

#### A. Methodology

The State's needs assessment process was conducted in a multi-faceted manner. Preventive and primary care services for pregnant women, mothers, and infants, and children were assessed by: 1) reviewing existing reports and surveys; 2) a careful examination of data; and 3) discussions among both professional and community leaders and groups. A Steering Committee was established for the Maternal and Child Health (MCH) component. The needs assessment for MCH had been initiated with the evaluation of Delaware's Smart Start and Kids Kare programs. Even though the needs assessment is required every five years, the assessment has been ongoing and continuous. The major needs assessment process occurred over the past year through the State's focus on MCH services as a result of Delaware's Infant Mortality Task Force.

For the Children with Special Health Care Needs (CSHCN) component, the Coordinating Council for Children with Disabilities (CCCD) was the advisory group. The needs assessment process for CSHCN was initiated by a working agreement in 2004 with the CompCare team of Health Systems Research, Inc. The objectives of the project were to assess relationships among agencies and institutions which provided services to CSHCN, to identify gaps or shortcomings, and to promote better collaboration among the service agencies and the state systems. This council submitted their recommendations to the MCH Steering Committee.

Review of the needs assessment for MCH was held during the MCH Steering Committee meetings over the past five years; during the numerous IMTF meetings and subcommittee meetings from August, 2004 to the current time, and during the Coordinating Council for Children with Disabilities over the past four years.

#### **B. CSHCN Needs Assessment Process**

The Steering Committee for CSHCN is the Coordinating Council for Children for Disabilities consists of over 40 agency representatives and other persons including parents; physicians; nurses; social workers; service providers; representatives from the Division of Public Health, Division of Mental Retardation, Division of Management Services, and the Division of Social Services (Medicaid), in the Department of Health and Social Services; Division of Mental Health in the Department for Children, Youth, and their Families; Department of Education; DuPont hospital for Children; University of Delaware; March of Dimes; Interagency Coordinating Council; home visiting agencies; Family Voices and other private and public agencies.

The Children with Special Health Care Needs population is inclusive of children with varying levels of care and services. Children with special health care needs who reside in Delaware receive care and services from numerous programs and agencies. It was difficult to identify and assess the health care needs of all Delaware's special health care needs children since there is no one program that maintains a comprehensive data base. The needs assessment process was

initiated after the end of the last full five year needs assessment process. As a continuing process, the issues found to be significant were continued.

The state's CSHCN needs assessment process started with a technical assistance request from the MCH Bureau for Comp Care of Health Systems Research, Inc.

Representatives from the Delaware Coordinating Council for Children with Disabilities came together on 30 April 2002, to explore ways to strengthen the coordination of services for children with special health care needs (CSHCN) over three years of age. Discussions indicated that while there was an array of services, they were not readily available or easily accessible throughout the State. Also of concern was the lack of knowledge on the part of both providers and families of currently available services making coordination of care for CSHCN difficult

As a result of the consensus obtained at the stakeholders meeting, the Department of Health and Human Services requested assistance from the CompCare technical assistance initiative to strengthen the coordination of services for this population group by promoting collaborative relationships between the key agencies/programs that provide services for CSHCN. These collaborative relationships would help to ensure that comprehensive quality services were available including mechanisms that would facilitate seamless transitioning from one agespecific program to the next.

To better understand how to improve the coordination of services for CSHCN ages 3-21, it was necessary to first identify key agencies currently providing services for children and identify the activities they conducted. Telephone and on-site interviews with key staff from the identified agencies, programs, existing councils, task force groups and committees organized to address issues related to CSHCN were used to gather information about their respective systems, goals, programs, services and activities. In addition, interviewees were asked to describe their outreach activities and mechanisms in place for coordination with other programs and systems.

Four focus groups were planned with parents of CSHCN to obtain information regarding their perceptions of the strengths or the current CSHCN systems and their recommendations for improvement. The information gathered was then to be analyzed to determine fragmentation, duplication, gaps in transitions, and unmet needs in the provision of services to CSHCN. These findings were to be compiled into a report, which was to be shared with CSHCN stakeholders and used to determine next steps in the development of an action plan to improve the coordination of services for CSHCN for children over three years of age.

#### C. Early Intervention Needs Assessment

The Delaware Division of Public Health is the recipient of an Early Childhood Comprehensive Services (ECCS) grant awarded by the Federal Maternal Child Health Bureau (MCHB). The overall goal of this initiative is to strengthen the State's early childhood system of services for young children, birth to five, and their families. In an effort to assess the needs of families centered on the ECCS critical components of health care, social-emotional development, early care and education, family supports and parent education, DPH conducted 10 statewide focus groups of families with children, birth to age five, in June, 2004 with the assistance of Health Systems Research. The specific objectives of the focus groups were:

- Assess the experiences of families in accessing early childhood resources and services particularly health care, child care, child development services, parent education and family support;
- Identify avenues of support used by parents of young children and their perceptions of the adequacy of the supports available to them; and
- Obtain recommendations from parents for improving the way information is provided and for improving the resources and services that are available.

Ten focus groups were conducted in all; two groups were conducted in Spanish. Sixty-one parents and/or guardians participated, including fathers and grandparents who are the primary caretakers of young children. The group participants represented a diverse range of backgrounds and experiences.

# **D. MCH Steering Committee Needs Assessment Process**

The MCH Steering Committee consisted of various members from the Division of Public Health, Medicaid, the Department of Education, the Division of Child Mental Health, WIC, and the Department of Children, Youth and their Families and a parent/consumer. Members included the Northern and Southern Clinic Managers and staff. The final Needs Assessment report was shared with all the members and their respective agencies/programs. Additionally, after submission of the MCH Block grant the document will be shared with a variety of agencies and councils including the Interagency Coordinating Council, the Interim Committee of the Infant Mortality Task Force (IMTF), the internal Steering Committee for the IMTF and others as appropriate. Of note is that the membership of the MCH Steering Committee has remained constant over the years. The presence of the same core active participants has enhanced the needs assessment process.

The Steering Committee initially reviewed the purpose of having the specific Title V indicators especially related to the National and State Performance measures. The data forms from the MCH Block grant provided a basis to determine progess and trends both positive and negative. All other relevant data and information was used as back up and explanation for the specific measures. The pyramid of services was introduced to compare what was currently in places existing support , resources and activities for direct health services, enabling services, population-based services and infrastructure-building services.

# DIRECT HEALTH CARE SERVICES: (GAP FILLING)

Basic Health Services, Oral Health, Specialty Services for Children with Special Health Care Needs, School Based Health Center Services, Family

Planning, Preschool Diagnostic Development Nursery (PDDN)

#### **ENABLING SERVICES:**

Translation, Outreach, Health Education, Family Support Services, Case Management, Coordination with Medicaid, Smart Start, WIC, Education, Kids Kare, Child Development Watch, SIDS Support

#### **POPULATION-BASED SERVICES:**

Newborn Screening, Lead Screening, Immunization, School-Based Health Centers, Injury Prevention, Nutrition, Outreach/Public Education, Home Visiting Program, Covering Kids, Emergency Medical Services for Children

#### **INFRASTRUCTURE BUILDING SERVICES:**

Needs Assessment, Evaluation, Planning, Policy Development, Coordination, Quality Assurance, Standards Development, Monitoring Training, Systems of Care, Information Systems, Support for Perinatal Board, Support for Child Death Review Committee, Universal Newborn Hearing Screening, Medical Home Initiative, Respite Care Team The capacity to meet these needs through the MCH Block Grant funding alone was necessarily determined to be insufficient. The real capacity to meet the needs in the pyramid of services is found in the extensive and intensive partnerships and coalitions in Delaware.

Priority areas were selected by a two step process. First, the Coordinating Council for Children with Disabilities conducted a similar review of the pyramid of services with input from topic driven reports on issues related to CSHCN. The Council itself had reviewed the seven national goals for CSHCN, the state CSHCN plan, the SLAITS survey results specific to Delaware, and other related reports both state and national. In determination of priorities, the CCCD then reviewed quantitative data to three topic areas of focus: respites care services, transition services for young adults with special needs, and motor vehicle crashes. The CCCD submitted the results of their discussions to the MCH Steering Committee. Three new state performance measures were negotiated at the meetings. The Council composed measures to be specific and time framed, based in hard data consistently collected, and that were connected to Healthy People 2010 objectives.

Secondly, the MCH Steering Committee, which included three members of the CCCD, reviewed the three proposed new state performance measures during their needs assessment process. The MCH Steering Committee identified and reviewed the activities that addressed the priority areas including those listed in Figures 4a and 4b of the block grant as related to each state and national performance measure.

The formal collaboration process as described above included both the MCH Steering Committee and the CCCD as an advisory group. The process was enhanced as most if not all of the participants were also active with the ongoing Infant Mortality Task Force (IMTF). The IMTF was established by the Governor with the following goals:

- > Defining the infant mortality status of Delaware as compared to the nation and the region.
- ➤ Defining the disparities among races related to infant mortality and determining the reasons for the increasing disparity gaps.
- ➤ Identifying risk factors and underlying etiologies when possible.
- ➤ Reviewing scientific literature with the purpose of determining risk factors for infant mortality and best practices for prevention and intervention.
- > Determining and assessing the impact of relevant risk factors.
- > Increasing awareness of the scope of the problem among government officials, medical professionals, and the public.
- Improving coordination between and among public and private sector agencies.
- ➤ Recommending critical changes to the profile of, operations of, and support of the Delaware Perinatal Board.
- ➤ Identifying areas requiring additional research and education.

The results of the "Infant Mortality Task Force" have been finalized with the report and its recommendations forwarded to the Governor. The Infant Mortality Task Force was mandated to develop broad-based recommendations for the reduction of infant mortality in the state of Delaware. The recommendations have been based upon scientific evidence, defined partnerships, expected contributions, timelines, review, and evaluation. These recommendations

encompass but are not limited to charges to business, community, education, communities of faith, providers, insurers, and the government.

It became obvious that the IMTF from the beginning was not only looking at mortality and morbidity, but also all aspects of maternal and child health services in Delaware. The five subcommittees over seven months conducted a review of all data, reports, scientific research and best practices as related to interventions, prevention, systems of care and disparities. The IMTF and its subcommittees were staffed by public health facilitators and MCH subject matter experts. Because of the intensity and importance of the process, the entire IMTF Final Report with its recommendations is attached. The initial process of the IMTF was through a concept mapping methodology. Consumer input was heavily considered form the beginning. Comments from over 1200 consumers through the concept mapping process were accepted through a website established solely for that purpose. The final recommendations were a synthesis of information and data presented in a format requiring actions steps, start dates for each recommendation, intended impact, agency responsibility, and fiscal implications. The improvement of maternal and child health services is a three year plan. The final report also includes stories gathered form mothers and their families about real life experiences.

Delaware is a small state and concerns were raised that citizens not be over surveyed. For these reasons and cost factors, primary data was not gathered particularly for this grant application and needs assessment. Surveys that were already completed or in the planning stages were utilized such as the respite survey, and provider surveys. Community needs assessments also played a major role in determining state priorities. Data used included Vital Statistics Reports; Hospital Discharge Data; Youth Risk Factor Behavior Survey (YRBS); Behavioral Risk Factor Surveillance survey (BRFSS); Newborn Screening Data; Division of State Police; Reportable Disease Data; and School Based Health Center data. The State also reviewed the Needs Assessment Indicators as well, and incorporated this information into the overall plan.

# E. Strengths and Weaknesses of the Needs Assessment

Because of the complexity of the needs assessment process and the competing needs of the target populations, Delaware could not feasibly cycle through the phases from analysis to the monitoring of progress of the performance measures in a consistent manner. As discussed in the Annual Report, Delaware's Title V program continues to face some specific difficulties for implementing programmatic changes due to most of the funds are tied up in personnel allocation. This at times determines and at times constricts program implementation.

The strength of the process included an often parallel system of review of specific target populations by the NCH Steering Committee, the CCCD, the Early Childhood Comprehensive Systems Steering Committee, and the IMTF and its subcommittees. As already stated, an additional strength is that given Delaware is a small state most if not all of the participants of the MCH Steering Committee and the CCCD were also members of the IMTF. Staffing for all three was provided by personnel of the MCH program.

The process for the initial technical assistance with Health Systems Research excited the Coordinating Council for Children with Disabilities but the outcome was disappointing. A report is still pending from HSR based upon their contacts and discussions with all the key providers of service to CSHCN. The focus groups were never completed due to a multitude of reasons. A recent letter was sent to HSR but as yet the CCCD has not received a response.

However other issues that arose out of the last five year needs assessment have been addressed and reviewed by the CCCD as part of an ongoing needs assessment. One of the major issues was the apparent need for respite care services. A respite care team has been investigating the issue over the years and a draft final report delineating the needs has bee completed. In addition the issue of transition from young adult to adult health and social services has been a focus of investigation through the CCCD and the a separate Transition Committee of which the MCH Director and Director of CSHCN have been active participants over the years.

As has been discussed in the Annual Report, Delaware's Title V program faces some specific difficulties in implementing programmatic changes because most of the available funds are tied up in personnel allocation, which by its nature, determines and sometimes constricts program implementation. Nevertheless, despite these inhibiting factors, the state is able to make incremental program changes based on identified needs through partnerships and coalitions where MCH and CSHCN are at the table.

Finally, a weakness of the process was the lack of a rigid system to determine the "capacity" of the MCH program. Technical assistance has been requested for this issue in Delaware's Annual Report.

# 2. Needs Assessment Partnership Building and Collaboration

As the basis of Delaware's pyramid of services, Infrastructure building is prominent. The methods used to build and enhance partnerships between and among MCH programs in Delaware are included in this section as well as in the section that follows labeled "Infrastructure Building Services" for the total MCH population. The MCH program works in partnership with all of the following:

#### 1. Delaware Health Care Commission

The Delaware Health Care Commission is an independent public body that reports directly to the Governor and the General Assembly. It was established by the General Assembly in 1990 to develop a "pathway to basic, affordable health care for all Delawareans". Serving on the Commission are the Secretaries of Finance, Health and Social Services, Children, Youth and their Families, the Insurance Commissioner and six private citizens appointed by the Governor, the Speaker of the House and the President Pro-Tempore of the Senate. The Commission has administrative jurisdiction over the Delaware Institute of Medical Education and Research, which allows Jefferson Medical College to function as Delaware's medical school and over the Delaware Health Information Network, which promotes an integrated health information network. The Lt. Governor serves as the Chair.

The Health Care Commission has focused on several initiatives designed to increase access to healthcare for uninsured and underserved Delawareans, including the Community Healthcare Access Program, the State Planning Program, and an analysis of the safety net in Delaware. The Health Care Commission also convened a committee around mental health issues and published 'The Committee on Mental Health Issues Final Report.'

#### 2. Delaware Medicaid Office

The Delaware Medicaid Office is administered by the Division of Social Services. Under Delaware's Medicaid program there are two Medicaid Managed Care Organizations (MCOs) and Delaware Healthy Children Program (DHCP), Delaware's SCHIP program. Under the Medicaid managed care plan, Delaware residents chose between the Diamond State Partners, established in 2003 and managed by the state Medicaid office, or Delaware Physicians Care Health Plan, established in 2004 and managed by Schaller Anderson of Delaware, Incorporated. Both Managed Care Organizations offer identical Medicaid benefit packages. DPH works closely with DE Medicaid on a variety of issues, including access to health care coverage and medical homes for all children, including those with special health care needs, and pregnant women, oral health access, prenatal care access, Child Development Watch operations, and early childhood systems development. To date, 139,187 Delaware residents receive Medicaid services and 10,825 children are currently enrolled in the DHCP program.

#### 3. Delmarva Health Initiative

Four community partners, including three hospital systems (Beebe Hospital, Bayhealth, and Nanticoke) and the Division of Public Health Office of Primary Care, have joined forces to identify those without a medical home and to provide information to help them to access services. This partnership is responsible for developing and implementing the Rural Health Plan.

#### 4. Department of Education (DOE)

The Delaware Health and Social Services, and the Department of Education work collaboratively to develop programs promoting the health of children in Delaware. Examples include the delivery of EPSDT services in the school setting and in providing support for School-Based Health Centers. The Department of Education initiated a Coordinated School Health Coalition in 1999 that includes several commissions or task forces, based upon the CDC Coordinated School Health Model which include DPH participation. Currently there are three commissions: Health Education, Health Services, and Physical Education. Future commissions will include Nutrition Services, School Climate, Staff Wellness, and Counseling Services. Thus far standards have been developed for health education that can be used in other curricula such as reading or social studies. The Coordinated School Health Program Team is composed of a variety of health and education related agencies, private, and public including parents. They recruited school applicants to participate in a needs assessment of health needs in their respective schools. After identifying the specific needs, plans were developed to target those needs. The Department of Education (DOE) has also collaborated with DHSS in development of the Part C early intervention efforts. Staff are also housed and incorporated into the CDW team and serve as liaisons for transition and Individuals with Disabilities Education Act (IDEA B and C) issues. This year the Office of Health Services, DOE, in partnership with the DPH to provide training to school nurses on teen pregnancy prevention, lead poisoning, tuberculosis, immunizations, and public health

resources. Delaware has a comprehensive system of school nurses, with one in each school and most private schools. There are over 300 full and part time school nurses in Delaware that serve students in public and private schools. The Department of Education and the Division of Public Health have also in partnership, to provide training to the school nurses on bio-terrorism and emergency preparedness.

#### 5. DOE Head Start Collaboration Office

The DOE-Head Start State Collaboration Office and the Division of Public Health have also partnered under the Healthy Child Care America and ECCS projects to pilot the Partners in Excellence: Promoting Social and Emotional Competencies in Young Children (PIE) project in 15 Head Starts, ECAPs and child care centers statewide. The purpose will be to develop and utilize evidence-based social-emotional classroom strategies to promote resiliency and foster appropriate social-emotional well-being in young children.

# 6. Department of Health and Social Services (DHSS) Division for Aging and Adults with Physical Disabilities

This Division has the lead for Traumatic Brain Injury issues in the state. The CSHCN Director works closely with the Division to ensure that the needs of children are addressed. DPH has also worked with this division on a variety of initiatives for older women. Although the Division for Aging and Adults with Physical Disabilities maintains the lead for the adult TBI issues in the state, the Division of Public Health, CSHCN, is working through a Subcommittee of the Council for Person with Disabilities to address the pediatric TBI/ABI issues. The Division for Aging and Adults with Physical Disabilities has gained approved for a Traumatic Brain Injury Medicaid waiver for the adult population.

# 7. Department of Health and Social Services (DHSS) Division of Social Services Child Care Office

The Division of Social Services, Child Care Office manages the child care services to support families with young children to enable the caretaker to hold a job, obtain training or meet special needs of the child. Child care may also be provided in child abuse cases to help protect the child. The service is available for children from infancy through twelve years of age. DSS determines eligibility based on the need for service and income. The income limit is currently set at 200% of the Federal Poverty Level (FPL). DPH and DSS-Child Care Office have partnered to ensure that health and safety standards in all licensed child care centers and home statewide are improved through training, technical assistance and regulations. The DSS-Child Care Office is assisting DPH with funding to support the statewide network of child care health consultants in the coming fiscal year.

#### 8. DHSS Division of Developmental Disabilities Services (DDDS)

Division of Developmental Disabilities Services (DDDS), DPH collaborates with DDDS on Traumatic Brain Injury issues, respite care, and Child Development Watch operations. The DDDS provides an array of services for individuals with mental retardation and other specific developmental disabilities and their families, who meet eligibility criteria. This agency is currently partnering with DPH and other community partners to pilot universal developmental screening of all children under the age of five.

#### 9. DHSS Division of Management Services

This agency provides human resources, budget development, and evaluation services to other DHSS divisions. It also houses the Birth to Three Office, which provides administration for Part C.

## 10. DHSS Division of Substance Abuse and Mental Health

The Division of Public Health (DPH) works with this agency on women's health issues, planning a women's health conference, and infant mortality issues. There are five objectives related to alcohol and drug use in Healthy Delaware 2010.

#### 11. DHSS Division of State Service Centers

DPH has worked with this agency to improve the following programs designed to assist Delawareans, most in need and link to the appropriate community or state resources:

- The Delaware Helpline provides toll-free information and referral for persons seeking information about public and non-profit services.
- Dental Transportation Services, in cooperation with the Delaware school system, ensures that school-aged eligible low-income children are transported from school to dental clinics located in the state service centers
- Adopt-a-Family is a statewide program that aids families in crisis --- those struggling
  with illness, homelessness, domestic violence, poverty or unemployment. This year
  they partnered with DPH to include Back to Sleep and SIDS information to pregnant
  women and families with children under the age of one. They also partnered with
  DPH to provide Medicaid/SCHIP information to all families receiving school
  supplies for their children in the Fall of 2004.
- Car seat loaner program provides car seats to needy families.

#### 12. DHSS Division for the Visually Impaired

The DPH Child Development Watch works with DVI to provide service coordination for children with visual impairments or who are deaf and blind.

#### 13. Federally Qualified Health Centers

The Office of Primary Care is located in the Health Systems Management Section of DPH. The Health Systems Management Director assists as a facilitator to the Federally Qualified Health Centers and coordinates with the Family Health Section Director to ensure a variety of primary and preventive maternal and child health services.

The Office of Primary Care staff continue to work closely to ensure access to healthcare services for uninsured and underserved Delawareans. Delaware has benefited greatly from the President's Initiative to increase access to healthcare services through community health centers. Delaware now has two Federally Qualified Health Centers (FQHCs) in New Castle County (Henrietta Johnson Medical Center), one in Kent County (Delmarva Rural Ministries/Kent Community Health Center), and one in Sussex County (La Red Health Services).

#### 14. DHSS Office of Emergency Medical Services

The Office of Emergency Medical Services of the Emergency Medical Services Section, has coordinated with MCH, including CSHCN, regarding issues around emergency preparedness for children and with injury prevention. A Special Needs Alert Program has been activated to link CSHCN with the 911 system and the first responders within their community. There are four objectives related to injury and disability in Healthy Delaware 2010.

## 15. Department of Services for children, Youth, and Their Families

The Department of Services for Children, Youth, and Their Families (DSCYF) was created in 1983 to consolidate child protective (Division of Family Services, DFS), child mental health, and juvenile correction services within a single agency. Family Health Services (FHS) has maintained a cooperative relationship with this agency for joint planning of services. A Memorandum of Understanding (MOU) between the DPH and DFS establishes uniform criteria for responding to reports of abuse and neglect and delineates the responsibilities of DPH and DFS personnel. The MOU addresses the need for ongoing, collaborative training and joint case planning between personnel in each agency. DFS and DPH are co-located at several local sites where direct services are provided. DFS staff is also housed at both sites of Child Development Watch and are fully incorporated into the multidisciplinary assessment team. In addition, DPH has collaborated with the Office of Child Care Licensing to improve the training and support for childcare providers in the areas of health and safety and in the development of the early childhood comprehensive systems planning. The Division of Child Mental Health has a working relationship with School-Based Health Centers, works closely with center coordinators to ensure appropriate referrals and obtain training for staff, and has contributed to the development of the Maternal and Child Health grant.

#### **16. SSDI**

The SSDI program is part of the Health Systems Management Section within Community Health. The SSDI Coordinator serves on the MCH Needs Assessment Steering committee. Other activities, both planned and completed, include the completion of an inventory of resources available in Sussex County and the barriers experienced by the Hispanic population in accessing health care; completion of an oral health care needs assessment of pre-school and elementary school-aged children throughout the state; completion of a Community Health Profile for every community in Delaware and presentation of those profiles to community leaders; and collaboration with the state and community stakeholders in developing strategies for addressing identified needs derived from the MCH needs assessment.

# 17. Women, Infants and Children Program )WIC)

WIC works with the DPH and other agencies to provide services and ensure quality. For instance, WIC was instrumental in the formation of the Delaware Breastfeeding Advisory Board, which now operates under the perinatal Association of Delaware. WIC also works closely with teen pregnancy prevention programs to prevent additional pregnancies, with the Immunization program to esure compliance by their recipients, and with the march of Dimes program to provide information about folic acid.

#### 18. Perinatal Board

In November 1995, Governor Carper signed Executive Order Number 37 establishing the Delaware Perinatal Board. The Perinatal Board has over this past year disbanded while acting as an interim committee to assist with the preparation of legislation for a new *Healthy Mother and Infant Consortium*. The Consortium is the result of a major recommendation of the statewide comprehensive Infant Mortality Task Force.

# 19. Infant Mortality Task Force

The Infant Mortality Task Force was implemented with the following goals to include:

- Defining the infant mortality status of Delaware as compared to the nation and the region.
- Defining the disparities among races related to infant mortality and determining the reasons for the increasing disparity gaps.
- Identifying risk factors and underlying etiologies when possible.
- Reviewing scientific literature with the purpose of determining risk factors for infant mortality and best practices for prevention and intervention.
- Determining and assessing the impact of relevant risk factors.
- Increasing awareness of the scope of the problem among government officials, medical professionals, and the public.
- Improving coordination between and among public and private sector agencies.
- Recommending critical changes to the profile of, operations of, and support of the Delaware Perinatal Board.
- Identifying areas requiring additional research and education.

The results of the "Infant Mortality Task Force" have been finalized with the report and its recommendations forwarded to the Governor. The Infant Mortality Task Force was mandated to develop broad-based recommendations for the reduction of infant mortality in the state of Delaware. The recommendations have been based upon scientific evidence, defined partnerships, expected contributions, timelines, review, and evaluation. These recommendations encompass but are not limited to charges to business, community, education, communities of faith, providers, insurers, and the government.

# 20. Delaware Healthy Mother and Infant Consortium

Pending legislation, HB202 authorizes use of funds to improve maternal and infant health. In addition, the legislation establishes The Delaware Healthy Mother and Infant Consortium (DHMIC) to coordinate efforts to prevent infant mortality and improve the health of pregnant women and infants in the State of Delaware. DHMIC is a network of organizations and individuals that will provide statewide leadership and coordination of efforts to prevent infant mortality and improve the health of pregnant women and infants throughout Delaware. The Consortium's priorities and advocacy agenda shall be initially dictated by the recommendations contained in the report entitled "Reducing Infrant Mortality in Delaware – Recommendations of the Infant Mortality Task Force", released in May 2005.

# 21. Fetal and Infant Mortality Review Pilot Project

The Fetal and Infant Mortality Review (FIMR) pilot study was born out of an interest to help inform the Infant Mortality Task Force (IMTF) on the potential benefits of locally applying the national FIMR model, a process of reviewing fetal and infant deaths to address gaps in the systems of care that serve women, children and their families. Infant births that resulted in a death at Christiana Care Health System during 2003 were included in the study. The study was limited to one hospital for logistical ease and to facilitate medical record availability. Fifty-six potential infant death cases were identified that met these criteria; eight cases were excluded as being inappropriate for FIMR, and hence the final pilot study sample was comprised of 48 infant deaths occurring to 43 mothers. The proposed plan for FIMR is a starting point for discussion among the partners and stakeholders in Delaware committed to improving maternal and infant health outcomes. FIMR is a process that is adaptable to local needs and should be reviewed on a regular basis to best serve Delaware's communities.

#### 22. March of Dimes

The Family Health Services Director (Title V) had served on the Program Services Committee of the March of Dimes. The Family Health Services section staff voluntarily serves on various March of Dimes-Delaware Chapter (MOD) committees to improve the health of babies by preventing birth defects and infant mortality. There is current DPH representation on the Program Services, Grants Review and Community Outreach committees. These committees consist of representation from public and private agencies, business leaders, community advocates and family advisors. DPH has provided funding towards the annual prematurity summit which focuses educating the community and medical providers on the specific needs of families with premature or low-birth weight children and development of strategies to reduce the number of premature births. DPH will continue to collaborate with the March of Dimes in a joint effort to increase access to quality prenatal care, reduce the number of premature births and birth defects and improve health outcomes of all children. The MOD staff collaborates and serves on DPH's Infant Mortality Task Force and the Fetal Mortality Review Committee.

#### 23. Perinatal Association

The Perinatal Association merged with Children and Families First; these partners share a similar mission. Children and Families First conducts counseling, foster care, and the Resource Mothers Program. There are nine (9) Resource Mothers, three (3) down state and six (6) upstate. Children and Families First will continue the tradition of targeting women least likely to seek services and the uninsured. The majority of the staff is bilingual. Their role includes, but is not limited to, prenatal, postpartum, and newborn education, transportation to prenatal and pediatric office visits, and assistance with obtaining appropriate resources including insurance, house, and jobs. The merged partnership supports community Resource Mothers. PAD and DPH work as a team on shared client cases and work to provide each client with the most comprehensive care without duplication of activities. Resource mothers are paraprofessionals from the community who identify and assist mothers, their infants, and families with accessing needed resources. They serve as mentors/role models by teaching and demonstrating skills in a variety of areas including menu planning, budgeting, parenting, etc.

# 24.. Head Start and Early Childhood Assistance Program (EAP)

Head Start is administered by seven community-based organizations throughout the state. Early Childhood Assistance Programs (ECAP) are state funded programs administered by the Department of Education and operated by seventeen community based organizations throughout the state, including existing Head Start grantees, school districts, and other early education agencies. Approximately 1,875 children between three and five are served by the traditional Head Start program. Eight hundred fifty (850) four year olds are served by EAP and 40 are served in Migrant Head Start. All programs followed the federal Head Start Performance Standards. The Division of Public Health participates on the Head Start State Collaboration project, which was established to develop state level partnerships for planning and policy development for Head Start eligible children and their families. Priority areas include welfare reform, health access, childcare, social and emotional wellness, disabilities, educational opportunities, volunteerism, literacy, and homelessness. The Head Start State Collaboration Office director serves on the Early Childhood Comprehensive Systems grant (ECCS) steering and executive committees and Healthy Child Care America-Delaware (HCCA-DE) advisory committee. In 2005, HCCA-DE and the Head Start State Collaboration Office have partnered to provide funding and resources for the piloting of Partners In Excellence: Promoting Social & Emotional Competencies in Young Children (PIE) in 15 Head Starts, ECAPS and Child Care Centers statewide. An additional partner is the Devereux Foundation and one of the evaluation measures will utilize the Devereux Early Child Assessment (DECA) tool.

#### 25. Early Success

The Department of Education's Early Care and Education Office is a key collaborator with the Division of Public Health on the early childhood comprehensive systems effort. Initiated in 1998, Early Success was developed as the state's coordinated plan to address the early childhood issues of children, birth to eight, who received out of home care. The governor established an interagency resource management committee made of the cabinet secretaries from the Department of Health and Social Services, Department of Services to Children, Youth and their Families, Department of Education, Office of Budget, and the Controller General's Office. Additionally, the governor established the Delaware Early Care and Education Council, comprised of private citizens, and the Office of Early Care and Education (OECE) to ensure that Early Success goals and objectives were met. In an effort to provide a comprehensive approach of early childhood services to all families, the ECCS and the OECE, with full support from the Delaware Early Care and Education Council, have partnered to unify Delaware's early childhood initiatives and broaden the initial Early Success plan to include child health, social-emotional development, and expand family engagement domains. This will provide a statewide strategic plan that is comprehensive, coordinated and accessible to all children, birth to five, and their families. It will also enable the Division of Public Health to provide statewide leadership on child health and development issues through multiple public/private collaborations.

#### 26. Child Death Review Commission

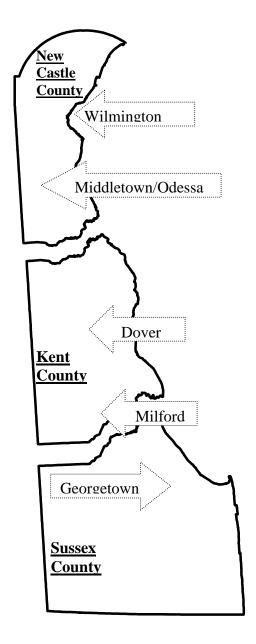
The Child Death Review Commission was signed into Delaware law on July 19, 1995. The Commission oversees the work of the two Child Death Review Panels, one for New Castle County and another for Kent and Sussex Counties. The Commission is composed of leaders from state agencies, police, nurses, physicians, attorney general's office, social workers, and child advocates. The Commission has the power to investigate and review the facts and circumstances of all deaths of children under 18, which occur in Delaware. Furthermore, it has the power to administer oaths and compel the attendance of witnesses. Its purpose is not to act as an arm of the police, but to look at systems to determine if the death was preventable. A death is considered preventable if one or more interventions might have averted it. The Commission legislation has been amended to now include child death, near death and stillborn. Efforts are in progress to establish a Fetal and Infant Death Review process in connection with the Child Death Review Commission.

The Director of CSHCN is also a member of three governor appointed councils related to persons with disabilities. Active participation on a number of other committees ensures collaboration and coordination. These include: the Interagency Coordinating Council, the Department of Education Child Outcomes Work Group, the ISIS data maintenance review, the IMTF, the ECCS Executive Committee, the Early Intervention Steering Committee among others.

The State also held meetings that helped to further define health needs. Particularly as health care pertains to pregnant women, mothers, and infants and children, the MCH Steering Committee determined that much work had already been accomplished during the past few years in assessing needs. Topical needs assessments already completed were utilized including provider and consumer surveys. Community needs assessments also played a major role in determining state priorities. Data used included Vital Statistics Reports; Hospital Discharge Data; Youth Risk Factor Behavior Survey (YRBS); Behavioral Risk Factor Surveillance survey (BRFSS); Newborn Screening Data; Reportable Disease Data; and School Based Health Center data.

In the future, the Pregnancy Risk Assessment Monitoring Surveillance Survey is being recommended within the Division of Public Health. There is some data that is not available to Public Health such as emergency room visit data, nonfatal injuries when not hospitalized, and some Medicaid encounter data. Another goal currently being planned is the full implementation of the Fetal Infant Mortality Review (FIMR) program. The pilot for FIMR has just been completed with a draft recommendation report being reviewed. Data and information from PRAMS and FIMR will greatly enhance the ongoing needs assessment process.

#### 3. Assessment of the Needs of MCH Groups



# A. Overview Of Delaware Demographics

The State of Delaware is located on the eastern seaboard of the United States. A small state encompassing just 1,983 square miles, Delaware ranks 49<sup>th</sup> in area among all states. Three

counties, New Castle, Kent, and Sussex, cover only 96 miles in length and 35 miles in width. The states of New Jersey, Pennsylvania and Maryland, as well as the Atlantic Ocean and Delaware Bay, border the State of Delaware.

Per 2003 data Delaware's total population is approximately 792,494. The majority (56%) of the population is between the ages of 20–59. The population aged 0-19 account for another 27% and, finally, those aged sixty (60) and up constitute the remaining 18%. It is interesting to note that since 1990, children ages 10 to 14 have increased by 29%. The population estimate for Delaware for 2004 was 830,364; a four percent increase. New Castle County increased by .01%, Kent County by 3.0%, and Sussex County by 2.2%. The population estimate for Delaware for 2010 is 838,913.

The top five employers, starting with the largest, include the State of Delaware, E.I.du Pont de Nemours and Company, MBNA Corporation, Christiana Health Care Systems and the Dover Air Force Base. The median income across the state is \$40,009 with the per capita income at \$15,854. According to the U.S. Census Bureau, in 1999, 10.4% of Delaware's population can be considered poor (less than 100% of the Federal poverty guidelines). 11.0% of all Delaware's children under 18 are poor (Three year average).

Census data shows that the state's median income grew by almost 5 percent to \$47,381 from 1989 to 1999. New Castle County had the highest median income at \$52,419, followed by Kent County at \$40,950 and Sussex at \$39,208. The median income in Sussex rose by 12.3 percent because an influx of older, wealthier, and better-educated retirees moved into beach areas. Overall, the data show significant gains in well-paying professional jobs because of the growth of service industries such as banking. However, the data also show that not everyone benefited from the decade's growth. The number of families living in poverty rose and the gap between the poor and the well to do widened. The number of families in poverty grew by 23 percent to 13,306 between the 1990 and 2000. The number of single mothers in poverty grew by 24 percent to almost 7,000 women. The percent of people in service occupations grew from 12.6 percent in 1989 to 14.6 percent in 1999. People in manufacturing jobs dropped by about 21 percent to about 12.5 percent. However, the new census figures show that the number of people in upper incomes grew in the past decade while the percentage of families in poverty also increased. In 2000, 63,663 Delaware households, or 21 percent, reported an annual income between \$50,000 and \$74,999, making that income groups the largest. In 1989, the largest percentage of the state's households - 20 percent - fell into the \$35,000-to-\$49,999 range. When adjusted for inflation, that range translates to Census 2000's \$45,425-to-\$64,892 bracket.

Between 2000 and 2001, the Division of Public Health pulled together a statewide partnership of over 150 Delawareans from business, community, health care, education, and government organizations to create the Healthy Delaware 2010 Initiative. A multi-sector steering committee established the vision and goals for the initiative and a collaborative process to develop measurable health improvement objectives for the decade. At the end of the process, over 60 private and public sector partners agreed to become "Prevention Partners" to involve their organizations, staff and members in the development and promotion of Healthy People 2010; work towards the achievement of health for all

Delawareans; and be active partners in the initiative. Several of the objectives and strategies of Healthy Delaware 2010 are in the MCH plan and are so referenced throughout this application.

# **B.** Population

- From 1990 to 2003, Delaware's total population grew 21.8 percent, an increase of 145,345 additional residents (see Table 1.1).
- During this period, the Sussex County population grew almost 47 percent.

Table 1.1 Total Delaware Population by County, 1990-2003

Source: Population Consortium

Area	1990	Percent	2003	Perce	ent	Population	on change	Percent change
Delaware	;	666,168	811,513	;	14	15,345		21.8
New Castle								
County	441,946	66.3	514,468	64.0	)	72,	522	16.4
Kent County	110,993	16.7	131,005	16.1		20,	012	18.0
Sussex County	113,229	17.0	166,040	20.5	5	52,	811	46.6
Total			100	•		•	100	

- The state's population grew more diverse in the decade from 1990 to 2000 (see Table 1.2). The state's nonwhite population grew from nearly 22 percent of the total population in 1990 to almost 28 percent in 2000.
- During this decade the state's Hispanic population more than doubled from 15,154 to 37,277. The state's black population increased more than 34 percent, a rate nearly triple that of the state's white population.

Table 1.2 Delaware Population by Race and Ethnicity, 1990-2000

Race	1990	Percent	2000	Percent	Change	Percent change
White, Non-Hispanic	535,334	78.6	584,773	72.4	49,439	9.2
Black, Non-Hispanic	112,125	16.5	150,666	18.7	38,541	34.4
American Indian	2,199	0.3	2,731	0.3	532	24.2
Asian	8,770	1.3	16,259	2.0	7,489	85.4
Other Race	7,740	1.1	15,855	2.0	8,115	104.8
Hispanic	15,151	2.2	37,277	4.6	22,126	146.0
	100	•		•	100	

Source: Census Bureau

- The minority population in New Castle County increased from nearly 20 percent of the county's population in 1990 to almost 27 percent in 2000 (see Table 1.3).
- Minority residents in Kent County grew from 22 percent of the county's population in 1990 to more than 26 percent in 2000.
- While Sussex County's other race category (primarily Hispanics) nearly tripled from 1990 to 2000, the county's white population grew from 70 percent of all residents in 1990 to 80 percent of the all residents in 2000.

Table 1.3 Population by Race by County, 1990-2003

New Castle	White	Percent	Black	Percent	All other races	Percent
1990	355,748	80.5	72,531	16.4	13,667	3.1
2003	376,034	73.1	110,300	21.4	28,134	5.5
Kent	White	Percent	Black	Percent	All other races	Percent
1990	87,298	78.7	20,633	18.6	3,062	2.8
2003	96,612	73.7	29,453	22.5	4,940	3.8
Sussex	White	Percent	Black	Percent	All other races	Percent
1990	92,288	69.3	18,961	14.2	1,980	1.5
2003	133,604	80.5	25,636	15.4	6,800	4.1

# Source: Population Consortium

• During the past decade, the growth rate among minority residents in New Castle and Kent Counties greatly exceeded the growth rate for the counties' white residents (see Table 1.4).

Table 1.4 Population Growth Rates by Race, 1990-2003

Area	White	Black	All other races
New Castle	5.7%	52.1%	105.9%
Kent	10.7%	42.7%	61.3%
Sussex	44.8%	35.2%	243.4%

# Source: Population Consortium

- The state population is projected to increase by 6.8 percent during the next seven years, resulting in an additional 55,015 residents (see Table 1.5).
- The growth rate for people over age 65 is expected to be twice that of any other age, adding 18,655 more seniors to the state's population.
- The youth population, age 5-14, is expected to decline slightly during the next seven years.

Table 1.5 Delaware Population Projections by Age, 2003-2010

2003	Percent		t	2010		Per	Percent		Change		ge	Percent change	e
Population		811	,513	3 86		866,528		55	5,0	15		6.8	
Age 0-4	53,	706	6.6	)	55,695		6.4			1,9	89	3.7	
Age 5-14	111	,224	13.	7	109,601		,	12.6		-1,6	523	-1.5	
Age 15-19	55,	472	6.8	3	59,281			6.8		3,8	809	6.9	
Adults (20-64)	482	,972	59.	5	515	5,157		59.5		32,	185	6.7	
65 years+	108	,139	13.	3	126	5,794		14.6		18,	655	17.3	

Source: Population Consortium

- The population projections for the next seven years reflect considerable variation in the population growth patterns by age within each county (see Table 1.6).
- New Castle County is expected to experience the largest increase in the number of youth age 15 to 19. This population is expected to grow 18.7 percent over the next few years.

- Sussex County is projected to experience a slight decrease in the number of youth age 15 to 19 over the next seven years.
- By contrast, Sussex County is expected to see a 22 percent increase in its population age 0 to 4 over the next few years.
- While New Castle County is projected to experience a slight decline in the number of residents over age 65, this group is expected to grow 13.6 percent in Sussex County through the remainder of this decade.

Table 1.6 Population Projections by Age and County, 2003-2010

Area	2003	2010	Change	Percent change							
New Castle											
Population	514,468	536,315	21,847	4.2							
Age 0-4	34,396	34,842	446	1.3							
Age 5-14	71,630	71,935	305	0.4							
Age 15-19	35,103	41,671	6,568	18.7							
Adults (20-64)	313,026	327,885	14,859	4.7							
65 years+	60,313	59,982	-331	-0.5							
Kent County											
Population	131,005	138,693	7,688	5.9							
Age 0-4	9,615	10,130	515	5.4							
Age 5-14	19,456	19,659	203	1							
Age 15-19	9,959	10,447	488	4.9							
Adults (20-64)	76,059	81,347	5,288	7							
65 years+	15,916	17,110	1,194	7.5							
Sussex County											
Population	166,040	189,061	23,021	13.9							
Age 0-4	9,695	11,865	2,170	22.4							
Age 5-14	20,138	21,615	1,477	7.3							
Age 15-19	10,410	10,033	-377	-3.6							
Adults (20-64)	93,887	109,310	15,423	16.4							
65 years+	31,910	36,238	4,328	13.6							

Source: Population Consortium

• Wilmington, the largest city in the state, is projected to experience a slight decrease in its overall population over the next seven years (see Table 1.7).

Table 1.7 Population Projections by Age, Wilmington, 2003-2010

2003	2010	,	(	Change	Percent change
Population	72,425	71,377		-1,048	-1.4
Preschool (0-4)	5,360	4,756		-604	-11.3

Adolescent (5-14)	10,281	9,991	-290	-2.8
School age (15-19)	5,102	5,391	289	5.7
Adults (20-64)	43,105	42,592	-513	-1.2
65 years+	8,577	8,647	70	0.8

Source: Population Consortium

#### C. Geographic Disparities

Although the state is relatively small, disparities exist across the counties with regard to access to quality health care services. Some of the problems are predominantly found in certain areas while others are common in each of the counties. For example, while it takes less than three hours to drive from one end of the state to the other, transportation is among the worst of the problems in each of the counties. Coupled with the geographic distribution of primary care physicians and dentists, this results in critical access issues. Racial, cultural and language barriers lead to access problems and place added burdens on the system.

Sussex County is the poorest in the state with an estimated 30% of its residents below 200% of the federal poverty level as compared to 23% for the rest of the state. The unemployment rate is also higher and the average income about \$8,000 less than the state average. Key informants note several communities in Western Sussex and south of Georgetown that have particular difficulties in accessing care including Frankfort, Clarksville, Selbyville, Hickory Tree, Seaford, Laurel and Bridgeville.

Places in Delaware other than the city of Dover, Kent County, while much smaller than Sussex County, is also mainly rural. Because of its population size, the county has been precluded from the benefit of federal designations necessary for eligibility into many federal programs. Kent County has had the lowest access rate to prenatal care in Delaware. Overall health services in the rural part of the state are more limited in availability when compared to northern New Castle County.

The city of Wilmington is like most urban areas throughout the nation and has correspondingly high rates of teen pregnancy rates, infant deaths, children born to single mothers, juvenile arrests and AIDS cases. Kids Count produced a fact book for the City of Wilmington and for the State of Delaware with a volume of data and trends related to Maternal Child Health. The City had a Public Health Officer for one year and the funding was cut. At the time there was a health consultant on board and she continues to be on contract directly to the Mayor's Office. Her role is to organize and guide the Mayor's Health Planning Council. The Council has been in existence for about six years. The consultant also organizes the Mayor's health initiatives, like his Healthy Walk with the Mayor monthly, the AIDS forum annually, the Wilmington Wellness day event and other activities of the Council. Areas of focus for Wilmington include: access to preventive care, chronic disease prevention, HIV/AIDS, mental health, responsible sexual behavior, substance abuse and violence prevention

#### D. Racial and Health Disparities

The Office of Minority Health for the Division of Public Health released a report on Health Disparities in Delaware in March of 2001. A Spanish version of the document was released in the fall of 2001. The following findings are significant:

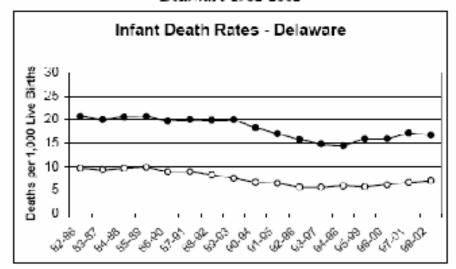
- There were three indicators where the rate for blacks was 3 times higher or more than the rate for whites: HIV Infection/AIDS Death Rate (10.66), Homicide Rate (4.3), and Asthma Hospitalization (3.3).
- Five indicators showed a disparity ratio of between 2 and 4: Teen Birth Rate (2.71), Late or No Prenatal Care (2.55), Per cent of Low Birth Weight Births (2.08), Infant Mortality (2.75), and Diabetes Death rate (2.47).
- Four indicators had a disparity ratio between 1 and 2: Alcohol-Induced Death rate (1.64), Stroke Death rate (1.62), Cancer Death Rate (1.45) and Heart Disease Death rate (1.20).

The Office also analyzed trends and determined that long-term downward trends were significant for late or no-prenatal care and alcohol-induced death rate. Trends have decreased in the short term for low birth weight births and teen birth rates. However, for all other indicators the disparity ratios have either changed or worsened.

On May 31, 2005 the Honorable Governor Ruth Ann Minner signed the Executive Order Number Sixty-Eight which established the Health Disparities Task Force. The Family Health Section, along with the Maternal and Child Health Branch and the Adolescent and Adult Health Branch, will be key participants in the Health Disparities Task Force. The goals of the Task Force include: defining the health disparities status of Delaware as compared to the nation and the region; documenting the disparities among racial and ethnic groups related to specific conditions and the reasons for the gaps; identifying best practices for prevention and intervention; increasing awareness of the scope of the problem among government officials, medical professionals and the public; improving coordination between and among the public and private sector; and identifying areas requiring additional research and education.

For the past 20 years, blacks have had infant death rates that were at least twice that of whites in Delaware. From 1982-86 to 1993-97 blacks and whites showed steady improvement towards reducing infant death rates. But since 1994-98, white rates have started to increase with black rates also increasing since 1995-1999. The black/white disparity ratio has remained well above two. While Delaware blacks remained much higher in the deaths per 100,000, the changes in yearly death rates closely mirrored each other.

Figure 3.15 Infant Death Rate by Race Delaware 1982-2002



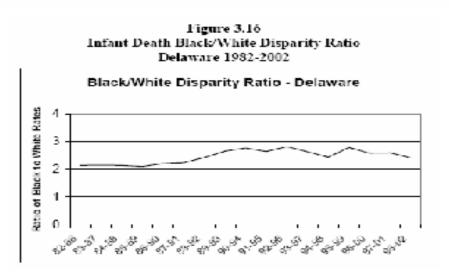


Figure 3.17 Teen Birth Rate by Race Delaware 1982-2002

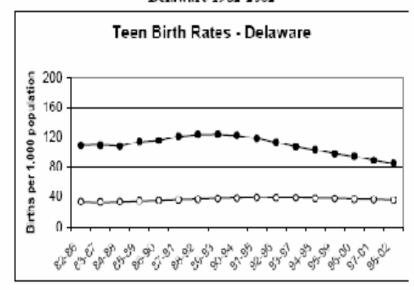
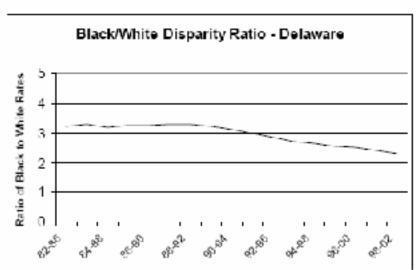


Figure 3.18 Teen Birth Black/White Disparity Ratio Delaware 1982-2002



In 1982-86 Teen Birth Rates for blacks were triple that of whites in the state of Delaware, and continued to increase gradually over the next seven years. Rates started to decline in 1990-94 and have continued to do so. Whites have maintained stable teen birth rates for the past twenty years in Delaware with about forty births per one thousand teenage girls. The black/white disparity ratio showed only slight reductions from just over 3 twenty years ago to a ratio of 2.35 currently.

Figure 3.19
Percentage of Late or No Prenatal Care by Race
Delaware 1989 2002

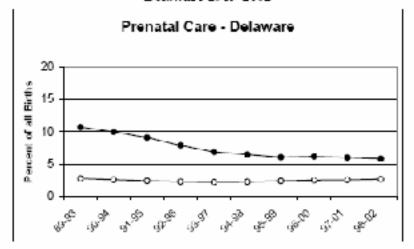
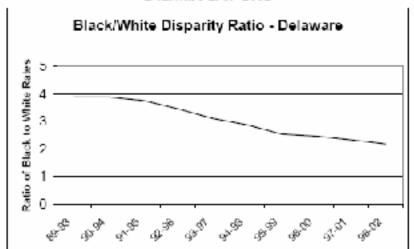


Figure 3.20 Late or No Prenatal Care Black/White Disparity Ratio Delaware 1989 2002



From 1989-93 to 1994-98 there was a steady decline in the percentage of births with little or no prenatal care in Delaware for blacks that have since plateaued from 1995 to the present. Whites remained at consistent levels that were well below the percentages of blacks. In 1989-93 blacks had a disparity ratio that showed blacks as being four times more likely than whites as having a birth with little or no prenatal care. The current level has since been lowered to just about twice the rate of whites and has been steadily falling for the last thirteen years.

Figure 3.21
Percentage of Low Birth Weight Births by Race
Delaware 1982-2002

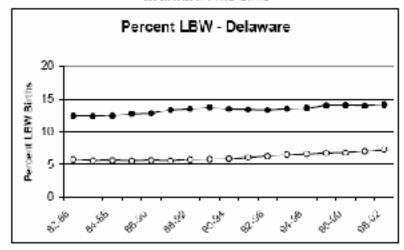
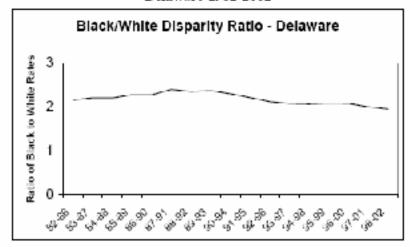
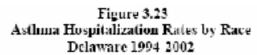


Figure 3.22 Low Birth Weight Black/White Disparity Ratio Delaware 1982-2002



Both blacks and whites have shown measured increases in the percent of low birth weight births in Delaware for the past twenty years. While blacks have shown a steady climb, whites have shown increases that started in 1988-92 and continue to 1998-2002. The black/white disparity ratio has consistently shown blacks as being twice as likely as whites of having a low birth weight baby. Blacks have started to close on the disparity gap despite the increasing numbers because of the surging low birth weight births for whites in Delaware.



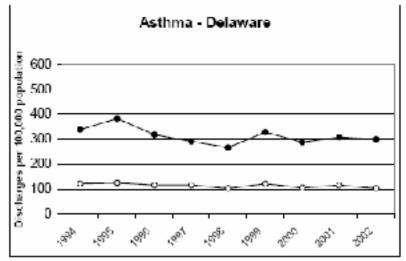
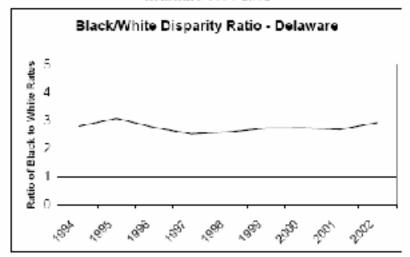


Figure 3.24
Asthma Hospitalization Black/White Disparity Ratio
Delaware 1994-2002



Blacks in Delaware have shown very little progress in reducing the asthma hospitalization rates per 100,000. Whites also have shown very little progress in reducing the asthma hospitalization rates, but whites maintain levels that are significantly lower than blacks. Over the last nine years blacks have shown both progress and recoil with asthma rates, but still maintain about 300 asthma hospitalizations per 100,000. The black/white disparity ratio has also shown very little change over the past nine years and blacks are still at a rate of asthma hospitalization that is three times that of whites.

The Delaware black/white disparity ratios are summarized in Figure 3.25 below.

Figure 3.25
Delaware Black/White Disparity Ratios

Indicater	DE 2002	DE 1997	US 2002	Trend
Heart Disease	1.16	1.11	1.30	Increase
Cancer	1.20	1 45	1.25	Decrease
Stroke	1.39	1.57	1.40	Decrease
Diabetes	2.33	2.33	2.14	No Change
HIV/AIDS	15.56	8.23	8 65	Increase
Homicide	3.94	3.56	5.67	Increase
Alcohol Induced	1.34	1.57	N/A	Decrease
Infant Death	2.41	2.63	2.48	Decrease
Teen Buths	2 15	2.74	1.86	Decrease
Prenatal Care	2.19	3.11	N/A	Decrease
Low Birth Weight	1.95	2.08	N/A	Decrease.
Asthma Hospitalization	2.93	2.53	N/A	Increase

Source: Center for Applied Demography & Survey Research, University of Delaware

#### E. Poverty

• Poverty guidelines are established annually by the U.S. Department of Health and Human Services (HHS) based on family size (see Table 2.1).

Table 2.1 2003 U.S. Department of Health and Human Services Poverty Guidelines

Size of Family Unit	Annual Income	Size of Family Unit	Annual Income
1	\$ 8,980	5	\$ 21,540
2	\$ 12,120	6	\$ 24,680
3	\$ 15,260	7	\$ 27,820
4	\$ 18,400	8	\$ 30,960

# Source: U.S. Department of Health and Human Services

- While the number of Delawareans living in poverty increased by more than 12,000 to 69,901 from 1990 to 2000, the percentage of Delawareans in poverty remained relatively constant over the decade (see Table 2.2).
- The percentage of Delawareans living in poverty is substantially lower than the national percentage.

Table 2.2 Number of People Living in Poverty, 1990-2000

Area	1990	Percent	2000	Number change	Percent	Percent change
U.S.	31,742,864	12.8	33,899,812	2,156,948	12.4	6.8
Delaware	57,223	8.5	69,901	12,678	8.7	22.2

Source: Current Population Survey, Census Bureau

- While New Castle County is home to more than 40,000 of the state's 70,000 residents living in poverty, New Castle County has the lowest poverty rate of the state's three counties (see Table 2.3).
- The number of Sussex County residents living in poverty grew by more than one-third from 1990 to 2000.

Table 2.3 Percentage of People Below Poverty by County, 1990-2000

Area	1990	Percent in the County	2000	Percent in the County	Number change	Percent change
Delaware	57,223	8.5	69,901	8.7	12,678	22.2
New Castle	33,268	7.5	40,710	8.0	7,442	22.4
Kent	12,071	10.8	13,083	10.1	1,012	8.4
Sussex	11,884	10.4	16,108	10.0	4,224	35.5

Source: Current Population Survey, Census Bureau

• In 2000, one-in-ten Delaware children under age 18, totaling 22,572 youth, live in poverty. This reflects a 17 percent increase from 1990 (see Table 2.6).

Table 2.6 Number of Children Under Age 18 Living Below Poverty, 1990-2000

Area	1990	Percent	2000	Number change	Percent	Percent change
U.S.	11,428,916	18.3	11,386,031	- 42,885	14.1	-0.4
Delaware	19,256	11.8	22,572	3,316	10.3	17.2

Source: Census Bureau

- In recent years, New Castle County has experienced a reduction in the percentage of children under age 18 living in poverty (see Table 2.7). This parallels a reduction in the percentage of children nationwide living in poverty.
- During the period from the mid-1990's to 2002, the percentage of Kent and Sussex County children living in poverty almost doubled.

Table 2.7 Three-Year Average Percentage of Children (0-17) in Poverty by County

Area	1989 – 1991	1994 – 1996	2000 - 2002
U.S.	19.9%	21.8%	16.4%
Delaware	11.9%	13.8%	14.6%

New Castle	13.2%	13.9%	9.2%
Kent/Sussex	10.8%	13.4%	23.3%

Source: Center for Applied Demography and Survey Research, University of Delaware

- The percentage of families in the city of Wilmington with children under age 18 living in poverty is nearly three-times that of New Castle County and double the rate in Kent and Sussex Counties (see Table 2.8).
- The percentage of Kent and Sussex County families with children under age 18 living in poverty is higher than in New Castle County.

Table 2.8 Families with Children Under Age 18 in Poverty, 2000

# of Families	Number i	<b>Poverty Rate</b>	
Delaware	105,081	10,403	9.9 %
City of Wilmington	9,444	2,276	24.1 %
New Castle County	68,286	5,736	8.4 %
Kent County	18,463	2,271	12.3 %
Sussex County	19,168	2,296	12.5 %
United States	13.	6 %	

Source: KIDS COUNT in Delaware Fact Book, 2003

- The percentage of families in the City of Wilmington with children under age 5 living in poverty is nearly three-times that of New Castle County as a whole (see Table 2.9).
- The percentage of Kent and Sussex County families with children under age 5 is approximately 50 percent higher than in New Castle County.

Table 2.9 Families with Children Under Age 5 in Poverty, 2000

Area	# of Families	<b>Number in Poverty</b>	<b>Poverty Rate</b>
Delaware	41,053	5,419	13.2 %
City of Wilmington	3,720	1,157	31.1 %
New Castle County	26,472	2,859	10.8 %
Kent County	7,415	1,216	16.4 %
Sussex County	7,149	1,344	18.8 %
United States		17.0 %	

Source: KIDS COUNT in Delaware Fact Book, 2003

• While the number of female-headed households in Delaware with children under age 18 living in poverty increased nearly 24 percent from 1990 to 2000 (an increase of 1,341 households), the percentage of these households living in poverty declined more than 5 percent (see Table 2.10).

Table 2.10 Female-Headed Households with Children Under Age 18 Below Poverty, 1990-2000

Area	1990	Percent	2000	Percent	Number change	Percent change
U.S.	2,866,941	42.3	2,940,459	38.9	73,518	2.6
Delaware	5,609	31.8	6,950	26.3	1,341	23.9

Source: Census Bureau

• There are 26,419 Delaware households headed by women with children under age 18. One-forth of these households live in poverty (see Table 2.11).

Table 2.11 Female-Headed Households with Children Under Age 18 Below Poverty

By County, 1990-2000

Area	199	0	Below overty	rcent	2000	Bel pov		Pero	cent	Nun cha		Percent change
Delaware	17,62	25	5,609	31.8	26,419	6,9	50	26	5.3	1,3	41	23.9
New												
Castle	11,62	25	3,202	27.5	16,777	3,9	91	23	3.8	78	39	24.6
Kent	3,19	93	1,257	39.4	4,832	1,4	61	30	0.2	20	)4	16.2
Sussex		2,807	1,150	0	41.0		4,81	0	1	,498		31.1

#### F. Medicaid

- Medicaid is a federally funded program that provides medical assistance to low-income individuals and families. Medicaid eligibility can be classified into five broad coverage groups: children, pregnant women, adults in families with dependent children, individuals with disabilities, and individuals age 65 and older.
- In the past two years, there has been a 16 percent increase in the Medicaid eligible population and an 18 percent increase in the number of Delawareans receiving Medicaid assistance (see Table 3.2).

Year	# Medicaid Eligible	# Receiving Medicaid
2001	104,745	100,404
2002	113,355	110,044
2003	120,977	118,775

Year	Households
1990	11,900
1992	17,869

1994	21,935
1996	21,043
1998	17,494
2000	13,849
2002	15,599
2003	18,267

Table 3.2 Monthly Average Number of People Eligible and Receiving Medicaid, 2001-2003

Source: Delaware Department of Human and Social Services

# **Food Stamps**

- The federally funded food stamp program assists income eligible families to meet their nutritional needs.
- According to the Department of Human and Social Services, there are 46,400 Delawareans receiving food stamps in 2003. From 2001-2003, the number of program beneficiaries in Delaware increased 45.4 percent (14,479 people).
- In 2003, there are 18,267 Delaware households receiving food stamp assistance. This is down from a high of nearly 22,000 households in 1994 (see Table 3.3). However, this reflects a 6,367 increase from the 11,900 participating households in 1990.

# Table 3.3 Number of Delaware Households Receiving Food Stamps, 1990-2003

Source: Delaware Department of Human and Social Services

# **Temporary Assistance for Needy Families (TANF)**

- Temporary Assistance for Needy Families (TANF) was created by the Welfare Reform Law of 1996. TANF became effective July 1, 1997, and replaced Aid to Families with Dependent Children (AFDC) and the Job Opportunities and Basic Skills Training (JOBS) programs. TANF is Delaware's main cash assistance program.
- TANF provides assistance and work opportunities to needy families by granting states the federal funds and wide flexibility to develop and implement their own welfare programs.

#### **Delaware Prescription Assistance Program (DPAP)**

- The Delaware Prescription Assistance Program (DPAP) began January 2000. This program, funded through tobacco settlement funds, provides up to \$2,500 per individual in each state's fiscal year for eligible clients. This program covers medically necessary prescription drugs for elderly and/or disabled individuals currently without prescription coverage. Program participants must have incomes below 200 percent of the poverty level or have prescription costs exceeding 40 percent of their income.
- In 2003, there are 5,524 people on average participating in the Delaware Prescription Assistance Program (see Table 3.5). From 2001-2003, there was a 70.2 percent increase in recipients, which has netted 2,279 new participants.

Table 3.5 Delaware Prescription Assistance Program, 2001-2003

Source: Delaware Department of Human and Social Services

<b>Monthly Average</b>	Children	Adults	Total
2001	10,194	3,404	13,598
2002	10,152	3,412	13,564
2003	10,505	3,609	14,114

Year	<b>Average Monthly Recipients</b>
2001	3,245
2002	4,878
2003	5,524

# **G.** Housing and Homeless

In 2000, there were 298,736 occupied housing units in Delaware (see Table 7.1). This reflects a 20.7 percent increase (51,239 units) from 1990 to 2000.

• The percentage of new units in Sussex County during this period was double that of the statewide increase.

Table 7.1 Number of Delaware Occupied Housing Units, 1990-2000

Amo	1990 Total # of occupied units	Percent	2000 Total # cf occupied units	Percent	Number change	Percent Change
Delawate	247,497		298,736		51,239	20.7
New Castle	164,161	66.3	188,935	63.2	24,774	151
Kent	39,655	16.0	47,224	15.8	7,569	19.1
Swssex	43,631	17.6	62,577	20.9	18,895	43.3
Percent		100.0		100.0		

Source: Consus Bureau.

• New Castle and Kent Counties have comparable occupancy rates (see Table 7.2). Both counties are close to ninety-five percent occupancy. In 1990, Sussex County occupancy rate was 58.8 percent; this jumped to 67.2 percent in 2000.

Table 7.2 Percentage of Occupied Housing Units by County, 1990-2000

Area	1990 Total bassing units	Fetal t of occupied units	Percent	2000 Tubil housing units	Fetal fret cocupied wants	Percent
Delaware	289,919	247,497	85.4	343,072	298,736	87 I
New Castle	175.560	164,161	94.6	199,521	188,950	94.7
Kent	42,106	39,655	94.2	50,481	47,224	93.5
Services	74,253	43.681	8.86	93,070	62,577	67.2

Source: Centus Bureau

• From 1990-2000, there was a 24.2 percent increase in owner occupied structures, while there was only a 12.3 percent increase in renter occupied structures in the state (see Table 7.3).

• There has been a modest increase in the number of owner occupied units, as a percentage of all housing units, throughout the state.

# 4. Pregnant Women, Mothers and Infants

# A. Major Health Issues, Gaps, and Disparities

#### Access to Care

The Delaware Health Care Commission, as described in the Annual Report, was formed to address health access issues. It was recognized at the time that while uninsured individuals were able to access health care thorough hospitals, that care was uncompensated. Hospital emergency care, however, cannot take the place of preventative and primary care managed by a primary care physician.

*Insurance Coverage:* Another report completed in 1998 (and repeated again in 1999) by the University of Delaware for the Delaware Health Care Commission identified populations without health care coverage in Delaware. One identified reason for problems with health care access is no health insurance. The tables below list characteristics of this population from both reports.

The characteristics of the uninsured change through the years. Between 1996-1998 and 1997-1999, the proportion of uninsured children increased; the proportion of uninsured women increased; the proportion of the working uninsured decreased; the proportion of those above the poverty line decreased; while the race and Hispanic proportions remained the same. These findings show that the approach to improving access to insurance must be multi-faceted. The Delaware Healthy Children Program could help to enroll children if their income is low enough, under 200% of the federal poverty level. However, it will not help those children whose parents are periodically unemployed or working but not covered by their employer and cannot afford coverage on their own. Significantly, 40% of those who are uninsured are working, although this per cent has decreased from 51% during the last period.

As with so many other health indicators, there are definite disparities in insurance coverage between racial groups. According to the study, black respondents have almost a 50% higher risk of being without insurance than white respondents do. Since Delaware's Hispanic population is low, data for Hispanics is subject to fluctuations. However, this study found that slightly less than 24% of Hispanics were without health insurance coverage which is double that for non-Hispanics.

- Delaware has a smaller percentage of children without health insurance compared to the U.S. (see Table 8.8).
- The percentage of children not covered by health insurance continues to decrease.

Table 8.8 Three-Year Average Percentage of Children Not Covered by Health Insurance, 1990-2002

	90 92	91 93	92 94	93 95	94 96	95 97	96 98	97 99	98 00	99 01	00 02
U.S.	13.0	12.7	12.9	13.4	13.9	14.3	14.5	15.1	14.8	13.6	12.4
DE	13.4	10.7	10.3	10.2	12.1	12.4	13.7	14.9	12.8	10.5	7.5

Source. Center for Applied Demography & Survey Research, University of Delaware, KIDS COUNT in Delaware Fact Book, 2003

• The percentage of all persons in the U.S. without health insurance has increased (see Table 8.9). • The percentage of all Delawareans without health insurance has declined.

Table 8.9 Three-Year Average Percentage of Persons (0-64) Without Health Insurance, 1990-2002

											00 02
U.S.	15.6	16.1	16.6	17.0	17.2	17.3	17.7	18.1	18.0	18.0	16.6 11.7
DE	15.7	14.2	14.0	14.2	15.8	15.8	15.7	15.7	15.7	15.0	11.7

Source: Center for Applied Demography & Survey Research, University of Delaware; KIDS COUNT in Delaware Fact Book, 2003

#### **Disparities**

There are disparities throughout the health system in access and for specific populations. Below are the most significant of those disparities.

*HIV:* As of 2004, there were 3,347 cases of AIDS reported in the state of Delaware from 1997 to 2001, the number of reported cases increased 39.7 percent. Intravenous drug use, and people having heterosexual contact with intravenous drug users, account for more than half of Delaware's AIDS diagnosis.

Delaware AIDS Cases by Year of Diagnosis and Year of Report, 1990-2004

Year		Yea	r Diagn	osed	Y	ear Reported
# of Ca	ses	Cumulative		# of Cases		Cumulative
1990	1	09	368		83	314
1991	1	26		494	90	404
1992	2	61		755	182	586
1993	266		1,021		383	969
1994	294		1,315		282	1,251
1995	278		1,593		299	1,550
1996	2	69	1,862		299	1,849
1997	2	21	2,083		170	2,019
1998	1	83	2,266		142	2,161
1999	<b>9</b> 168			2.434	177	2,338
2000	212		2,646		222	2,560
2001	1	74		2,820	260	2,820

2002	188	3,008	173	2,993
2003	209	3,217	213	3,206
2004	130	3,347	141	3,347

Source: HIV/ AIDS Epidemiology, Division of Public Health, Delaware Health and Social Services

Delaware's HIV/AIDS epidemic continues to disproportionately affect the Black population. Blacks comprise 19% of the state population but 66% of AIDS cases and 64% of HIV cases. Among females, 80% of AIDS cases and 69% of HIV cases are among Blacks, compared with 59% and 64% nationally. The national vs. Delaware comparison is even more striking among males where 62% of AIDS cases and 61% of HIV cases are in the Black population in Delaware, compared to the national percentages of 35% and 43%, respectively. For pediatric cases, 71% of both HIV and AIDS cases in Delaware are within the Black population. National data on gender/race breakdowns were unavailable for pediatric cases.

*Diabetes:* Data shows that Diabetes is high in Delaware particularly among African-Americans. In 1997, the Behavior Risk Factor Surveillance System (BRFS) reported that 6.4% Delawareans have diabetes. 6.9% of women reported having it as opposed to 5.9% men. However, 9.5% non-white females reported having diabetes. Mortality rates are also high, particularly in Sussex County. The five-year annual average 1993-1997 age adjusted mortality rate per 100,000 was 53.7 for black females in Sussex County. The overall average for black females in Delaware was 38.9. The overall rate for white women was 11.8 and 13.3 in Sussex County. According to birth certificate records, 3.7% of the births in 1997 were to mothers who had diabetes. Data does not break down the numbers according to whether the diabetes was gestational or preexisting. Also, since there were concerns with the consistency of reporting from the state's hospitals, this data is no longer reported.

Diabetes has grown to almost epidemic proportions in Delaware according to statistics released by the Delaware Public Health's Diabetes Control Program. This state ranks 15<sup>th</sup> in the nation in the overall rate of diabetes. This means that nearly 82 people out of every thousand have diabetes. It gets even worse as ages increase. The rage more than doubles for individual between 54 and 64 years (166.7 per 1000) and peaks at 204.4 per 1000 after the age of 65. Though Delaware is one of the smallest states in the country, it has the fourth highest death rate of all the states. Additionally, African-Americans had a death rate up to three times higher than that for Caucasians.

To help combat the rapidly growing incidence of diabetes and to limit the devasting results of the disease, over the next year Cheer will conduct an ambitious Diabetes Intervention Program. The program's goals will be to forestall the onset of diabetes, better control existing cases, and diminish complications from diabetes for Sussex County citizens age 50 and older. The effort will be especially concentrated in the western part of the county, where the incidence of diabetes is highest.

To address Delaware's high rate, the state House of Representatives created a Diabetes Task Force. This group identified four barriers: education and awareness; access to coverage/obstacles to benefit coordination; labor intensive navigation of the system; and psychosocial factors. The

Division of Public Health's Diabetes Control Program has developed seminars, support services and training for families and community leaders on current treatments for diabetes management and disease prevention strategies. Also the Division has provided free health screening and assessment for participants in the community intervention. The initial target population was African-American adults 35 and older in Sussex County. The Division has worked with a group of community leaders to form the Delaware Diabetes Coalition that is dedicated to reducing the burden of diabetes and its complications in Delaware. The coalition in collaboration with three managed care organizations developed a patient and provider flow sheet to promote the use of quality standardized care. The flow sheets identify for both the patient and the provider routine procedures, tests and specialists visits that are necessary to reduce the complications of diabetes.

Asthma: Asthma can be considered as an indicator for primary care and overall child health in that with proper case management and adherence to proper regimen, occurrences can be minimized. As previously stated, this is another area where disparities between whites and blacks is very evident. Blacks in Delaware have shown very little progress in reducing the asthma hospitalization rates per 100,000. Whites also have shown very little progress in reducing the asthma hospitalization rates, but whites maintain levels that are significantly lower than blacks. Over the last nine years blacks have shown both progress and recoil with asthma rates, but still maintain about 300 asthma hospitalizations per 100,000. The black/white disparity ratio has also shown very little change over the past nine years and blacks are still at a rate of asthma hospitalization that is three times that of whites.

Delaware's Behavioral Risk Factor Survey has been collecting data on asthma since 2000. In the 2002 BRFSS, 14% of Delaware adults reported they had been told by a doctor or health professional that they had asthma at some time in their lives. A 2003 child asthma supplement to the BRFS indicated that approximately 45,000 households in Delaware have at least one child with diagnosed asthma. In 2004, about 14.4% of Delaware adults reported having been told by a doctor or health professional that they had ever had asthma. About 10% of the state's adult population reported currently having asthma. The rate of children hospitalized for asthma (10,000 children less that five years of age). The asthma hospitalization rate has stayed relatively the same over the last three years.

## Geographical Disparities: Access to Care

Overall health services in the rural part of the state are more limited in availability when compared to the northern New Castle County.

Sussex and Kent Counties: Sussex County is the poorest in the state with an estimated 30% of its residents below 200% of the federal poverty level as compared to 23% for the rest of the state. The unemployment rate is also higher and the average income about \$4,000 less than the state average. Key informants note several communities in Western Sussex and south of Georgetown that have particular difficulties in accessing care including Frankfort, Clarksville, Selbyville, Hickory Tree, Seaford, Laurel and Bridgeville.

The Office of Rural Health, in the Health Systems Management section of DPH with the Delaware Rural Health Initiative developed the Delaware Rural Health Plan. The plan was developed by reviewing available data and reports and interviewing key stakeholders. The result was an environmental analysis of the county's multiple resources including sufficiency, quality,

and gaps. Regarding the MCH population, the plan noted some of the following gaps in resources:

- Monitoring of outcomes is limited.
- Provider to provider communication is sporadic.
- More bilingual capacity is needed.
- Services for CSHCN are limited in that there are not enough specialists and providers
- Transportation limits access.
- Adolescent access into family planning services is problematic due to lack of transportation and availability of clinic hours.

The Division of Public Health contracted with the University of Delaware's Center for Applied Demography and Survey Research to survey primary care physicians in the state with the resulting report, Primary Care Physicians in Delaware 2001. Primary care physicians (PCP) include the following specialties: family practice, general practice, internal medicine, pediatrics, and obstetrics/gynecology. The overall findings as they relate to MCH include:

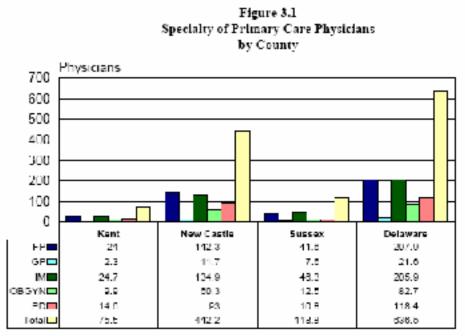
- There are probably sufficient primary care physicians in Delaware (1231:1) although their location and specialty is probably not optimal.
- While there are currently sufficient numbers today, those numbers are at the upper range of what is desirable (1250:1) and Kent County (1678:1) is well above that target now.
- There may be a need to encourage more Hispanic physicians and Spanish-speaking physicians and staff, as that population grows more numerous in the state particularly in Sussex County.
- About 84% of primary care physicians are accepting new patients but the proportion accepting new Medicare and Medicaid patients (67%) is significantly lower. This also varies by practice specialty.
- More than half of primary care physician's time is devoted to serving Medicare and Medicaid patients while they represent less than 20% of the population.
- Wait times for appointments vary significantly between established and new patients and also by county. There are also significant differences between the specialties.
- Only about 45% of primary care physicians employ non-physician services from advanced practice nurses, physician assistants, and others.
- About 23% of Delaware's primary care physicians do not belong to any managed care network. The rate is highest in Kent County (29%).
- Primary care physicians are fairly well distributed in sub-areas of the county. The only exception to this finding is for OBGYNs.

## **Practice Characteristics**

The 739 primary care physicians in Delaware are distributed across different specialties and have different types of practices. In this section, some of the key characteristics of those practices are discussed. The attributes selected for analysis largely relate to capacity and

availability for patient care.

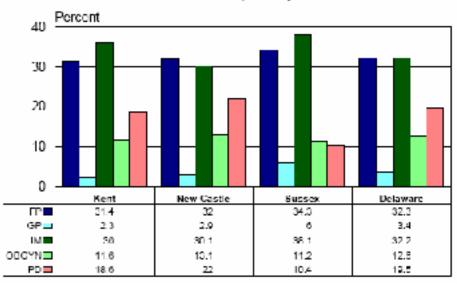
While in theory primary care physicians deliver similar services, they also practice in their reported specialties. Figure 3.1 contains the estimates for these specialties by county.



Source: Center for Applied Demography & Survey Research, University of Delaware

No one specialization really dominates the distribution. In general the number of physicians in internal medicine is roughly equivalent to those in family practice. Those classified as general practitioners are declining and the vast majority of those are over the age of 65. The number of OBGYNs and pediatricians in Kent and Sussex counties is clearly showing a different pattern. Some of this can be attributed to different demographics in the two counties in that residents of Kent County are generally younger. The differences in the percentage distribution shown in Figure 3.2 below also reflect these findings.

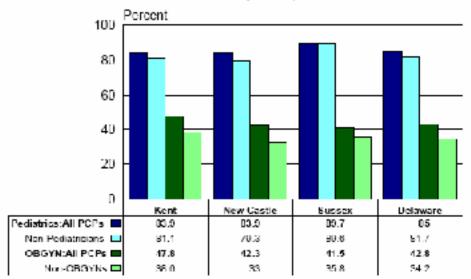
Figure 3.2 Distribution of Primary Care Specialties by County



Source: Center for Applied Demography & Survey Research, University of Delaware

The distribution in Figure 3.2 shows that primary care physicians are distributed essentially in three major groups. One third are family/general practitioners; one third are internists who focus on adults; and one third are primary care physicians focused on smaller groups of patients. About 50% of pediatricians stop seeing patients when the patients reach 18 years of age and the balance will cease treatment by age 21. Similarly, OBGYNs are generally concerned with female patients. It is interesting to see that Sussex County has a significantly larger proportion of primary care physicians in the "full-service" group. Primary care physicians with family practice or internal medicine specialties may provide pediatric and OBGYN services. The extent of this crossover between the specialties is shown in Figure 3.3, below. First of all, the table needs some explanation. The lines labeled *Pediatric* and *OBGYN* include all primary care physicians. The lines directly beneath exclude the specialists in those areas. Thus, 83.9% of primary care physicians in Kent County provide pediatric services and 81.1% of non-pediatric primary care physicians provide those services. Perhaps the most interesting part of this information is that a larger proportion of non-OBGYN physicians are providing OBGYN services in Kent County. This is consistent with the much smaller proportion of OBGYNs available in Kent County. In contrast, the same cannot be said for pediatric services in Kent County. There are relatively more pediatricians in Kent County than elsewhere, however the proportion of non-pediatric physicians providing those services is not lower as would be expected. Clearly this is a more complex issue than can be adequately addressed here, however it certainly relates to the younger age distribution in Kent County.

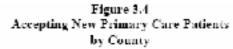
Figure 3.3 Provide Selected Specialty Services by County

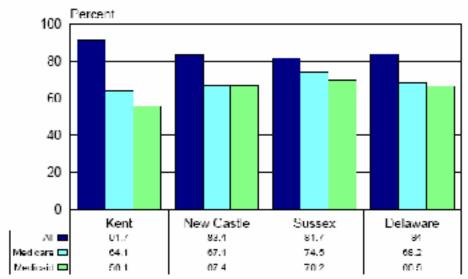


Source: Center for Applied Demography & Survey Research, University of Delaware

One of the most critical issues with respect to the capacity of primary care physicians is whether they are accepting new patients. The data with respect to this question is found in Figure 3.4 below. Between 81% and 92% of primary care physicians report that they are accepting new patients. The proportion is lowest in Sussex County. The more interesting point is which specialties are accepting new patients. More than 90% of OBGYNs and pediatricians are accepting new patients. In contrast, 81% of family and general practitioners are accepting them, while about 84% of Internists currently are accepting new patients.

Primary care physicians were also asked if they were accepting new Medicare and/or Medicaid patients. Those results are also found in Figure 3.4, below. A cautionary note is needed for interpreting the Medicare results. Pediatricians comprise almost 20% of primary care physicians. However, they only see a very small set of Medicare patients, i.e. those situations where one of the special programs allows a child to have access to Medicare through SSI (Social Security Insurance). In reality, about 80% of non-pediatric primary care physicians are accepting new Medicare patients in contrast to the 68% indicated in the table. Still, that is well below the estimates for all patients. This may reflect the fact that older patients will occupy substantially more of a given physicians time than younger patients. There are significant differences between the specialties. The acceptance rate ranges from 75% for family practice to 81% for OBGYN.



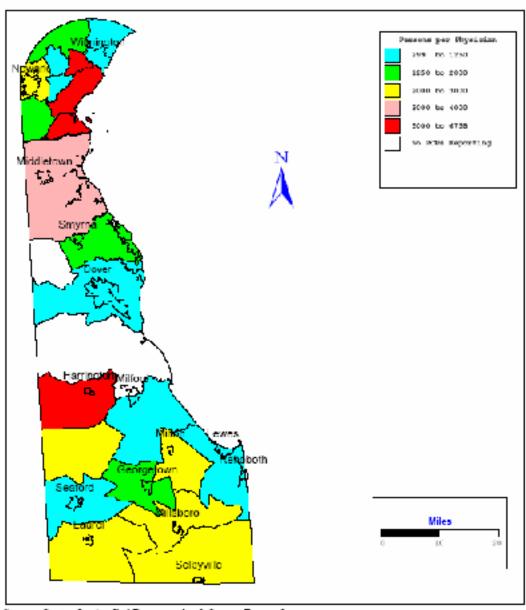


Source: Center for Applied Demography & Survey Research, University of Delaware

The results regarding the acceptance of new Medicaid patients are similar to those for Medicare but without the cautionary note. There are differences between the counties and with physicians in Kent County being the least willing to accept new patients of this type. The fact that Kent County has the fewest primary care physicians per person undoubtedly influences this result. Further, there is a significant difference between the specialties with acceptance of new Medicaid patients varying from 63% for family practice to 89% for pediatricians.

# Number of Persons per Primary Care Physician by Census County Division

Source: Center for Applied Demography & Survey Research, University of Delaware
Figure 4.1
Number of Persons per Primary Care Physician
by Census County Division



Source: Center for Applied Demography & Sorvey Research, University of Delaware There also seem to be some problems attracting new physicians into Southern Delaware which may lead to a shortage as the current group ages and as the population grows, particularly in Sussex County. Slightly more than 80% of primary care physicians are accepting new patients but the proportion accepting new Medicare and Medicaid patients is significantly lower. This also varies by practice specialty. In Kent County, there is a difference of over 44 percentage points between those PCPs currently treating Medicaid patients and those willing to accept new ones. Sussex County fairs slightly better with a difference of about 28 percentage points. One reason for this difference is that more time is necessary for these patients. Statewide, about 24% of overall physician time are spent on Medicaid patients. However, only 12% of the total population are Medicaid eligible. The difference in physician time is not unexpected, since most eligibles are children. Above is the map showing the distribution of primary care physicians in the state of Delaware.

Another area of need in Southern Delaware is mental health. As a study done under the auspices of the Developmental Disabilities Planning Council by Elwyn, Inc. Mental Health Study for Delaware, Population Ages Birth to 24 reported that key informants in the mental health communities in Kent and Sussex Counties pointed to a lack of services providing behavioral health care in either the private or public sectors. The draft Rural Health Plan lists other concerns:

- Ambulatory chemical dependency and substance abuse services appear to be insufficient;
- Child and adolescent services are insufficient;
- Wellness Center staff report significant access problems for mental health services for children and adolescents
  - No formal process is available for adolescent behavioral health referrals or for linkages between primary care and behavioral health resources
  - There is 0.5 FTE child psychiatrist in the county, located on the coast; there are no pediatric or adolescent behavioral health units or hospital services in Sussex County
  - Knowledge of, and linkages between resources (communication), in the child and adolescent population are lacking

*New Castle County:* There are pockets throughout New Castle County where access to health care is a problem. In addition to Wilmington, the largest city in the state, there are other areas where poverty, lack of transportation, cultural barriers, etc. are common. These areas include the Rt. 40 corridor, the Middletown-Odessa-Townsend (MOT) area, and Claymont.

The MOT area needs mental health services, services for cancer patients, and transportation. This area has gone through remarkable growth in the last 10 years with many middle and upper middle class families building homes in the MOT area. It has one of the few school districts that are adding new schools. It added a new high school a few years ago and plans to add a new kindergarten and grade school. However, services have not kept pace with the growth. Physicians who come to the area to practice have no trouble filling their waiting rooms. Despite the influx of the well-to-do families, there are economically disadvantaged areas in all three towns where joblessness, alcohol, and drugs have been the norm.

The Route 40 corridor is an area of small developments inhabited by the working and non-working poor. Not only is transportation not routinely available, but there are no stores or

activities that are in walking distance. In fact, walking on Route 40 is dangerous because there are no sidewalks and the traffic moves quickly.

Claymont in Northern New Castle County is an urban area where there are pockets of poverty and transportation is more difficult than in the city. Using public transportation, it can take as much as a full day for a person living here to get to and from a clinic.

*City of Wilmington:* The city of Wilmington is like most urban areas throughout the nation and has correspondingly high rates of teen fertility rates, infant deaths, children born to single mothers, juvenile arrests and AIDS cases. Although Wilmington does not have a city health department, it has recently focused more on the health needs of its population and has recently hired a Public Health Officer.

DPH and Wilmington worked together to assess need through a Health benchmarking project. Key informants (about 40 people) were interviewed throughout the city of Wilmington to identify the key areas of need in the city.

The results were summarized into seven main focus areas:

- Improving youth and adolescent health
- Supporting Healthy Behaviors
- Improving Access to health care
- Environmental Health
- Monitoring Wilmington's Health
- Creating a Health Structure for the City
- Improving the health of older adults

Although Wilmington has major hospitals and available physicians, access to care remains a problem in the following areas:

- Locations and service times which are not convenient
- Transportation which is not accessible or affordable
- Too few culturally competent health care providers, preferably bi-lingual
- Lack of pharmacy services for the uninsured and under-insured
- · Lack of Dental care
- Few Ancillary services
- Lack of health insurance coverage

As a result of creating a health structure group, the city created a Public Health Officer position. The Public Health Office has recently created a vision also based on findings of the Benchmarking process. Of note in regards to the MCH population are:

- To coordinate with the state agencies the flow of information pertaining to health issues including, but not limited to, diabetes, sexually transmitted diseases, mental health, infant mortality, and lead contamination.
- To help with the educational effort promoting responsible sexual behavior tending to reduce teenage pregnancy.
- To help find answers to the problem of substance abuse which must include alcohol and tobacco agendas and addressing the tobacco use among adolescents.

- To help community organizations formulate programs addressing the issues of physical activity and obesity/overweight
- To help promote healthy communities.

In addition, the city created the Physician Advisory Board for the Mayor, which the Director of Public Health co-chairs. As a result of the monitoring health work group, the city contracted with Kids Count and the University of Delaware to produce Wilmington Counts.

In October 1999, the City of Wilmington and Wilmington Healthy Start held a Housing Roundtable for Pregnant and Parenting teens. Needs identified were: domestic violence programs, child care and after school care, case management, emergency assistance, transportation, coordination and collaboration between lead agencies, health insurance, substance abuse services, health services near housing, safe environments, budgeting and lifeskills training, stress management, and parenting.

## **B.** Program Capacity by Pyramid Levels

## 1.) Direct Care Services and Enabling Services

## **Access to Care**

Of great concern in Delaware has been access or early entry into care for pregnant women in Kent County. Delaware uses the Kessner Index to determine access to care and just this year used the Kottechuck Index as well. Both show an across the board reduced access to care.

There are no clear-cut answers to this situation. The Division of Public Health and the Office of Health Statistics are working closely with the newly to be formed Healthy Mother and Infant Consortium and Kent County providers to determine root causes and to address them. Initiation of the PRAMS survey may help. The Infant Mortality Forum final report has more details on access to care.

#### **Financial Access**

## Impact of Medicaid and managed care

Satisfaction with Health Care Plans: Satisfaction with health care plays a large role in accessing care. If an individual is dissatisfied with her doctor, she may not enter into care as soon as she should. If she is unaware of what her health care plan pays for, she may not attempt to access a needed service. The Delaware Health Care Commission funded a Consumer Assessment of Health Plans Study (CAHPS) in Delaware. A major component of the study was a survey of adults, age 18 and above, about their experiences with their health plan and medical care during the previous six months. At the time of the survey, 74% of Delaware's non-elderly adults were enrolled in some form of managed care.

This survey followed one that had been conducted in 1997 but more people were surveyed allowing for more detailed comparisons. One key finding was that Delawareans are more satisfied with their health plans than they were in the prior year. The 1998 findings also

showed a statistically significant difference in satisfaction between managed care and fee for service enrollees. Fee for service enrollees were more satisfied. This was a change from the previous year when there is no statistically significant difference. Interpretations for this gap are that the enrollees remaining in fee for service are likely to be the most satisfied with their plan; survey sample increase; deteriorating managed care quality which seems unlikely that it would drop so much in one year; and the "bashing" of managed care in the media. On the other hand, overall ratings of health care and ratings of specialists show no significant differences between managed care and fee for service. For most of the specific measures used by the survey, there was no difference between managed care and fee for service. Even though the survey was dated, it reflects the current status of the impact of managed care.

**Benefits:** The Medicaid managed care plans (Diamond State Health Plan) cover all of the basic Medicaid services as well as enhanced care for pregnant women called Smart Start and comprehensive EPSDT services. Post partum home visits are also required under the plans. Family planning benefits are extended for all women with Medicaid for two years after they lose eligibility for comprehensive coverage. Freedom of choice for family planning services is still protected so that a woman may go to any qualified provider for family planning services regardless of the plan in which she is enrolled.

As Medicaid participants begin utilizing their medical homes and primary care providers, there is much less demand upon public health to provide direct medical services at public health clinics, although this varies in each county. All pregnant women, regardless of insurance status, identified as "at-risk" may obtain Smart Start services that are currently provided through three agencies including DPH. Because of the new stricter federal regulations, Medicaid cannot pay for Smart Start services to undocumented immigrants, although Medicaid funds can pay for basic treatment. Funding for DPH Smart Start services is provided through Title V, Medicaid and revenue dollars.

The switch from fee-for-service Medicaid to managed care, has limited some of the opportunities for DPH to come into contact with these women and enroll them in programs such as Smart Start. However, other methods have been developed such as co-locating DPH staff in OB-GYN offices. Another area of concern is that managed care companies have established authorization procedures that are cumbersome and difficult to track. They also have had difficulty in retrieving reliable encounter data from physicians. Public Health staff have recently been meeting with the MCOs to share some of their experiences with establishing encounter data systems, tracking clients, and ensuring that patients receive follow-up check-ups. In addition, one of the two remaining managed care providers has recently switched to fee-for-service for its enrolled physicians which may help to provide the necessary data to track program success.

## **Cultural Acceptability**

Cultural issues often present barriers in providing health services. Throughout the state a major issue is the language barrier. Languages spoken include numerous Spanish dialects, Pakistani, Chinese, Creole, Haitian, Korean, Vietnamese, and several African dialects. Even AT & T's third party translation program faces difficulties with the Spanish language

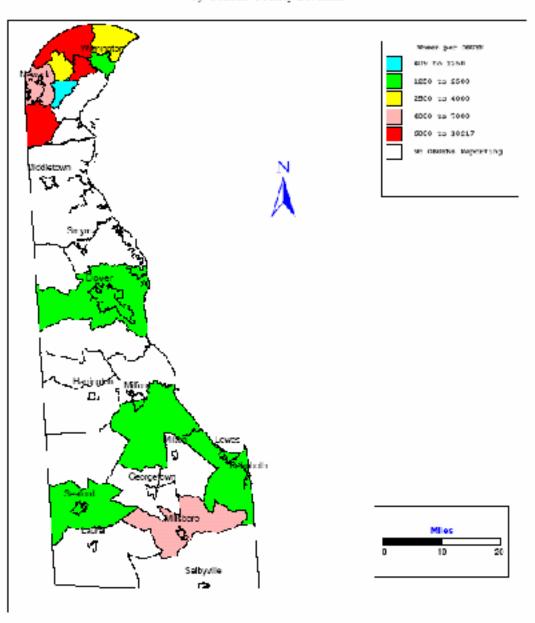
because there are so many dialects that exact translation is impossible and the translators do not know how to translate medical terminology. Such translation also takes a lot of time and receptionists say they do not have time to use the service. Hospitals have only sporadic translation services. Often they call upon a family member without a health background and in many cases children. In at least one instance, a child attended the birth of his sibling so he could translate for his mother.

Other cultural differences exist which present other problems. For instance, some cultures object to a man coming into the home to give a child therapy if the man of the house is not home. Although he may request a woman therapist, the agency may not have one. Also women coming from other countries, such as Guatemala, have not had a physical exam. Some of these women have come to family planning clinics and have been shocked that they would need to be examined. These issues require not only sensitivity from staff but time to work with the woman to help her achieve a comfort level with the exam.

# Availability of Prevention and Primary Care Services *OBGYNs:*

Primary care physicians have available to them resources to extend their own abilities to serve patients. The advanced practice nurse (APN), the certified nurse midwife (CNM), and the physician's assistant (PA) are the most typical such resources. There are significant differences between the specialties where the OBGYN and pediatric primary care physicians are far more likely to employ all of these alternative resources. (See below for more detail.)

Figure 4.3 Number of Women (15-64) per OBGYN by Census County Division



Source: Center for Applied Demography & Survey Research, University of Delaware *Midwifery:* There are less than 20 midwives in Delaware. The Birthing Center in northern New Castle County employees the services of midwives who deliver about 80 babies a year. A few years ago, Kent General Hospital closed its maternity center which included midwife services. The Division of Public Health participated on a transition committee which worked to ensure that private doctors were ready to take additional patients and to ensure that the uninsured receive services. OB/GYN Associates worked with the state to enhance their available services.

# Service Area #1: Primary Care Needs

- Sussex County is currently designated as a Medically Underserved Area (MUA), and as a Primary Care Low Income Health Professional Shortage Area (HPSA). Designation is based in part on the overall number of full time equivalent (FTE) physicians.
- According to the Primary Care Physicians in Delaware Report (PCP Report, 2001), which
  was compiled by the University of Delaware's Center for Applied Demography and Survey
  Research:
  - There is one FTE primary care physician per 1,231 people in Delaware; 1:1,318 people in Sussex County; and 1:1,678 people in Kent County.
  - The number of FTE primary care physicians has increased in each of the counties between 1998 and 2001:

	1998	2001
Delaware	610	636.5
New Castle	429	442.2
Kent	72.3	75.5
Sussex	108.7	118.8

- Eight percent of the primary care physicians in Sussex County are of Hispanic origin, which is higher than the state (4.3); New Castle County (3.9); and Kent County (1.3).
- The estimated need for additional primary care providers differs when taking a "by the numbers" view versus documenting the experience reported by individuals related to "limited practical access or availability" of numerically adequate providers. Access may also be compromised due to the following factors:
  - Practices may be closed to new patients.
  - Practices may accept limited insurance (public health insurance, such as Medicaid and State Child Health Insurance Program (SCHIP), as well as commercial).
  - While the federal criteria for FTE (hours of practice per week) are met, productivity is not considered (i.e., low productivity would effectively reduce capacity).
  - Typical hours of operation (no evenings or weekends).
  - Lack of knowledge or skill in the care of special populations (e.g., disabled, child/adolescent, AIDS, and geriatrics.
  - The primary care capacity is clustered around hospitals, especially for OB/GYN services, thus making access geographically difficult for some citizens –

- particularly those lacking private transportation. This geographic problem is institutionalized, to some degree, by hospital credentialing rules requiring physicians to live within 30 miles of the hospital.
- Cultural accessibility (Hispanic population) and multi-lingual capacity are limited.
- The University of Delaware, Center for Applied Demography and Survey Research compiled the most recent Delawareans Without Health Insurance report in 2001 (DWHI Report).
- According to the DWHI report, approximately 10.9% of Sussex County residents are uninsured. This is slightly higher than New Castle (10.5%), and lower than Delaware (11.3%) and Kent (15%).
- According to the DWHI report, approximately 88,000 Delawareans are without health insurance. Of that, 16,000 are from Sussex County, 20,000 are from Kent County and 52,000 are from New Castle County.

## Service Area #1: Primary Care Resources

## **Summary of Findings: Primary Care Gap Analysis**

- <u>Awareness</u>: Hospitals make medical staff directories available and provide information on available primary care practices. DPH developed and distributed a *Health Care in Delaware* brochure, which provides information on available resources statewide (including Sussex County).
- Access: Improvements have been made to access/intake. Sussex County has numerically adequate capacity, but problematic geographic distribution. Fewer than 37% of PCP sites have Spanish bilingual capacity. 26% of Sussex County PCPs do not participate in a managed care network. Primary care access for special population is problematic. Providers treat 92.4% of Medicaid patients with 70.2% accepting new Medicaid patients. Providers treat 88.8% of Medicare patients with 74.5% accepting new Medicare patients. Recruitment of health individuals to provide primary "well care" remains problematic.
- <u>Direct Service</u>: Primary care services are available through private providers, hospital based providers and community health centers. La Red Health Center opened in 2001 and is serving approximately 3,000 customers annually. The Kent Community Health Center (Delmarva Rural Ministries) provides primary care services in Dover.
- <u>Referral</u>: Linkages with behavioral health, geriatric specialists, and dental services remain questionable.
- <u>Monitoring</u>: The 2000 Consumer Assessment of Health Plans in Delaware measures quality and accessibility to primary care and gave Sussex County a quality rating of 7.9 (out of a possible 10) while managed care organizations received a quality rating of 7.7 (out of a possible 10).
- Infrastructure: Hospital bylaws require physicians to reside within 30 miles of hospital.
- <u>Leadership</u>: Delaware Rural Health Initiative (DRHI) will provide a leadership role. Hospitals, the Division of Public Health, the Delaware Health Care Commission (including DIMER), and physician organizations have taken a leadership role in increasing primary care access.

- <u>Planning</u>: The Delaware Health Care Commission (DHCC) has taken a coordinating role in recruiting health care professionals and having data available.
- Communication: Communication across all provider networks has improved.

# **Availability of Speciality Care Services**

Alcohol and Drug Abuse Programs: According to a study completed by the University of Delaware for the Division of Alcoholism, Drug Abuse and Mental Health, Prevalence and Need for Treatment of Alcohol and Other Drugs Abuse Among Women in Delaware, lack of research regarding drug abusing women has made it difficult to develop programs specifically geared to women. However, studies have shown that female-specific programs have a higher success rate.

Reflections, the substance abuse center at Governor Bacon located in Delaware City, New Castle County, has a capacity of 12 mothers and 4 infants. Infants must be under 6 months when the mother enters treatment, as the facility is not functional for toddlers and older children. This is the only residential treatment center available exclusively to women.

## 2.) Population-Based Services

## **Newborn Screening**

This program is responsible for identifying, in the newborn period, certain disorders which, if untreated, result in mental retardation and other disabilities. Our efforts include screening services for over 31 disorders provided at the birth site prior to discharge and repeated between 7 and 28 days. Delaware Public Health regulations require that all babies be screened. However, regulations permit families to decline screening for their baby if their religion prohibits such testing.

DPH county field staff will continue to support the screening program by providing follow-up in the home when screenings have not occurred in the hospital (i.e., home births) or a repeat screen is needed. While most repeat screens are completed in the hospital, a referral is made to Public Health Nursing for a home visit if an infant with an abnormal HMD cannot be located.

The state will continue to screen for Phenylketonuria (PKU); Congenital Hypothyroidism (CH); Galactosemia, Hemoglobinopathies, Biotinidase Deficiency, and Maple Syrup Urine Disease (MSUD).

The Expanded newborn screening will continue, however, because of ethical considerations, only those problems that can be treated are tested. They are Homocystinuria, MSUD, Tyrosinemia, Urea cycle disorders, other aminocidopathies, MCAD, other Fatty acid oxidation, Methylmalonic academia, Proprionic academia, Isovaleric academia, Glutaric aciduria 1, other organic aciduria, and G6PD deficiency.

Funding Mechanism: Newborn Screening dollars are generated through revenue.

*Geographic Availability/Distribution:* Delaware has an outstanding record in meeting this need. Every birthing hospital participates.

## **Universal Newborn Hearing Screening**

This program is responsible for assisting Delaware birthing facilities to achieve the goal for every baby to have a hearing screening prior to discharge. Our efforts include coordinating activities with the Delaware Infant Hearing Assessment and Intervention Program, centralizing hearing screening data and tracking, and providing follow-up on babies who fail the screens. All Delaware birthing facilities provide hearing screening prior to discharge.

Regulations for the Birth Defects Surveillance and Registry Program require the reporting of all birth defects including hearing impairments. All Delaware birthing sites voluntarily screen the hearing of newborns and report results using a system set up by the Newborn Screening Program office. Ninety-eight percent (98%) of the babies born in Delaware were screened for Newborn Hearing. The Newborn Hearing Screening program identified twenty-one infants with a hearing loss in 2004.

The Hearing Aid Loaner Program loaned out hearing aids to 2 babies diagnosed with a hearing loss. Program information was placed on the Newborn Hearing Screening website to ensure the utilization of the program.

A data committee was developed to undertake our ongoing problems with definitions, and how to break out the data. The data committee will decide what "lost to follow up" means and what data should be reported at the state and hospital level.

With the DE Newborn Hearing Screening Program in place all DE babies who are referred for diagnostic evaluation as a result of their hearing screening will be followed through the Program Office. The Central Reader's Station at the program office records all pertinent information and the Newborn Hearing Coordinator contacts parents, providers, and the Medical Home. Birthing facilities receive Quality Assurance Reports from the Program and scheduled visits. The program aims to achieve a goal of 100% diagnosis for all babies referred and 100% amplification for all babies diagnosed with deafness or hearing loss.

Funding Mechanism: Funding for hearing screens is primarily through federal grants.

*Geographic Availability/Distribution:* Hearing screens are provided at the six birthing sites, the tertiary care hospital for children, the Birth Center and the midwife for the Amish.

## **Breastfeeding Promotion**

The WIC program supports the reinforcement of the WIC National Breastfeeding Campaign, Loving Support Makes Breastfeeding Work through local media, and the distribution of pins, pens, banners, posters, baby blankets, breastfeeding resource texts, and other marketing materials to those agencies, employees, participants and facilities that participate in the project. Clients receive encouragement, information, and education from WIC, Family Planning, and Smart Start visits in the home. WIC contracts with the three theatres to run the Loving Support Makes

Breastfeeding Work logo as a slide prior to feature films. Presentations by the Breastfeeding Coordinator are ongoing.

Breast feeding is a topic included at multidisciplinary assessment in nutrition discussions. DPH facilitates obtaining breast pumps, special formulas as needed for special needs infants.

Funding Mechanism: Funding depends on the specific program. WIC is a federally funded program.

Geographic Availability/Distribution: Promotion is available throughout the State.

#### Folic Acid

The March of Dimes provides leadership to the Folic Acid Coalition. The Folic Acid Coalition continues to function. The committee meets quarterly and the last meeting was June 27, 2005. Current projects are as follows:

- 1. The committee is meeting with Panama Partners with the intention of sharing our Folic Acid promotions with Panama.
- 2. Folic Acid Man/Woman is a trademarked promotion developed by the Folic Acid Coalition of Delaware. Rights are held by the Delaware Chapter of the March of Dimes. In addition the coalition developed an activity book, Adventures of Folic Acid Man, which meets the curriculum guidelines for middle school students and is available for teachers.
- 3. March of Dimes mailer to OB/GYNs and family practice docs will include 2 folic acid pieces.

Funding Mechanism: The coalition activities are funded primarily through a March of Dimes (MOD) chapter grant to Christiana Care's Community Based Women & Children's Health Services.

Geographic Availability/Distribution: This effort is a state-wide campaign.

## **Home Visiting Program**

Delaware offers the Home Visiting Program to all first time mothers of newborns. Home visits are conducted by several home health agencies. If a second home visit is needed, these can be undertaken by a variety of agencies based on identified needs. Second visitor agencies include Baby Steps, Parents as Teachers, Public Health's Second Visitor programs, and Community-Based Parent Education and Support.

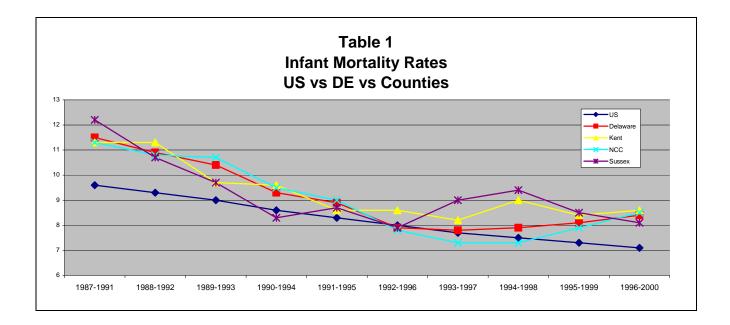
Funding Mechanism: Funding for this program is provided through State General Funds.

Geographic Availability/Distribution: Services are provided to all new mothers.

## Lifecycle #1 – Needs of the Infants and Perinatal Population

• Key outcome indicators of infant and perinatal health care effectiveness are the neonatal/infant mortality and low birth weight (LBW) rates.

- In Sussex County, infant mortality and neonatal mortality dropped during the last two 5-year periods.
- Low Birth Weight has continued to rise from a favorable level (pre-1995) to approach the higher state rate.
- The Sussex County infant mortality rate (8.1) is higher than the US (7.1), but lower than Delaware (8.4) and New Castle County (8.5)<sup>1</sup>. See Table 1. Kent County has the highest infant mortality rate (8.6).
- Infant mortality rates represent the number of deaths to children under one year of age per 1,000 births.

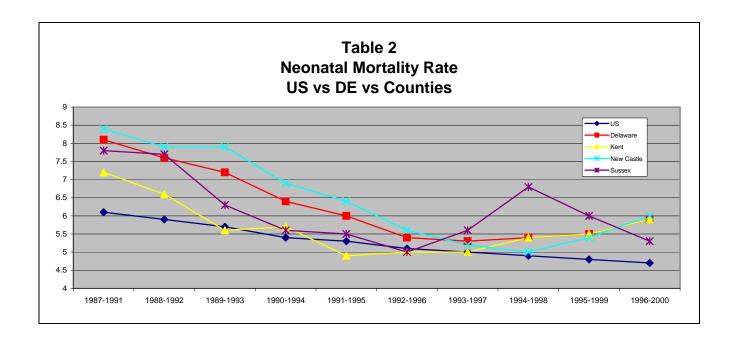


- The Sussex County neonatal mortality rate (5.3) is higher than the US (4.7), but lower than Delaware (5.9), Kent County (5.9) and New Castle County (6.0)<sup>2</sup>. See Table 2.
- Neonatal mortality rates represent the number of deaths to children under 28 days of age per 1,000 live births. Causes are usually very low birth weight or congenital anomalies.

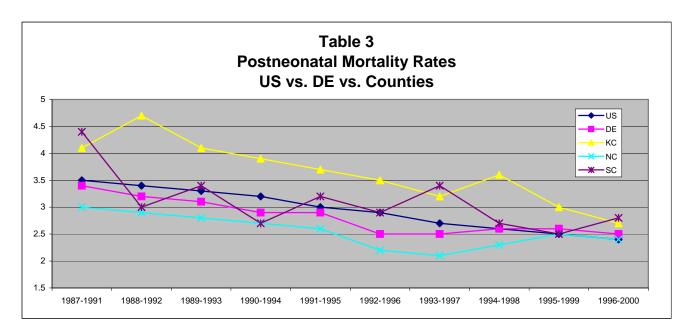
-

<sup>&</sup>lt;sup>1</sup> Table E-4, *Delaware Vital Statistics Annual Report*, 2000, page 196.

<sup>&</sup>lt;sup>2</sup> Table E-5, *Delaware Vital Statistics Annual Report*, 2000, page 199.



- The Sussex County postneonatal mortality rate (2.8) is higher than the US (2.4); Delaware (2.5); Kent County (2.7); and New Castle County (2.4)<sup>3</sup>. See Table 3.
- Postneonatal mortality rates represent the number of deaths to children 28 to 364 days of age per 1,000 live births.

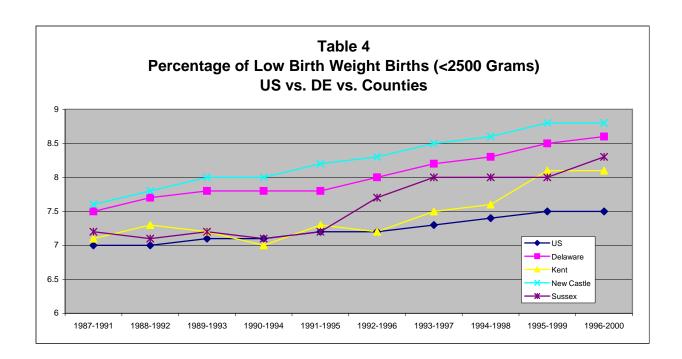


• The Sussex County low birth weight percentage (8.3) is lower than the state (8.6) and New Castle County (8.8) but higher than the nation (7.5), Kent County (8.1). <sup>4</sup> See Table 4.

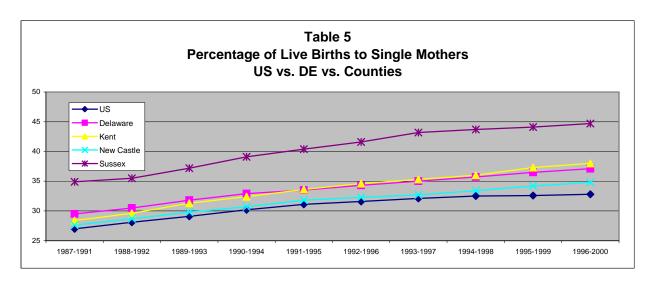
56

<sup>&</sup>lt;sup>3</sup> Table E-6, *Delaware Vital Statistics Annual Report*, 2000, page 201.

<sup>&</sup>lt;sup>4</sup> Table C-37, Delaware Vital Statistics Annual Report, 2000, page 100.



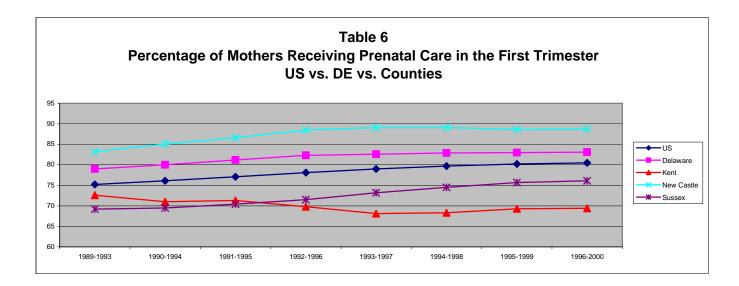
• The Sussex County percentage of live births to single mothers (44.7) is higher than the nation (32.8); the state (37.1); New Castle County (34.8); and Kent County (38.0). <sup>5</sup> See Table 5.



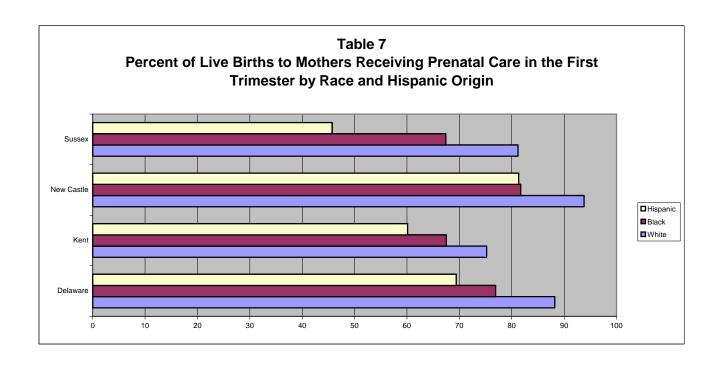
• The Kent County percentage of mothers receiving prenatal care in the first trimester (69.4) is lower than the nation (80.5); the state (83.1); New Castle County (88.7); and Sussex County (76.1)<sup>6</sup>. See Table 6.

<sup>&</sup>lt;sup>5</sup> Table C-17, *Delaware Vital Statistics Annual Report*, 2000, page 79.

<sup>&</sup>lt;sup>6</sup> Table C-49, Delaware Vital Statistics Annual Report, 2000, page 117.



- Black women in Kent and Sussex Counties are less likely to receive adequate prenatal care.
- The Sussex County percentage of births to Black mothers beginning prenatal care in the first trimester (67.4) is lower than the state (76.9); New Castle County (81.7); and Kent County (67.5). The Sussex County (67.5). See Table 7.
- The Sussex County percentage of Hispanic mothers receiving prenatal care in the first trimester (45.7) is lower than the nation (71.4); the state (69.4); New Castle County (81.3); and Kent County (60.1). <sup>8</sup> See Table 7.



<sup>&</sup>lt;sup>7</sup> Table C-51, *Delaware Vital Statistics Annual Report*, 2000, page 119.

58

<sup>&</sup>lt;sup>8</sup> Table C-53, Delaware Vital Statistics Annual Report, 2000, page 123.

# Lifecycle #1 Update

- Access to Care: The La Red Health Center opened in Georgetown in 2001 and is providing primary care and maternity services. The Kent Community Health Center in Dover received federally qualified health center status in 2002 and is planning to add maternity services in the future.
- <u>Monitoring</u>: The Delaware Vital Statistics Annual Report is used to monitor the reported indicators. The infant mortality rate is rising initiatives are underway between the Division of Public Health and the Perinatal Board to research causes and implement strategies to reverse this trend.

#### 5. Children and Adolescents

#### A. Major Health Issues, Gaps, and Disparities

# 1.) Delaware Early Childhood Focus Group Study Findings and Recommendations

The recommendations based on the collective findings and concerns of the groups were as follows:

- 1) Steps Need to Be Taken to Improve the Process by which Families Obtain Information about Early Childhood Services and Resources.
  - Strengthen Existing Sources of Information
  - Train Providers of Early Childhood Services to Be More Effective at Dispensing Information and Making Referrals
  - More Information needs to be available in Spanish
  - Families need to be informed of services and resources on multiple occasions
- 2) Services and Information should be targeted at all families in Delaware.
  - All Income Groups-parents with diverse incomes often need support and assistance on availability of resources and information.
  - Hispanic Families- State agencies and other programs should work collaboratively with existing services targeted at Hispanic communities to ensure a broad range of services and develop trusting relationships with this fast-growing population.
  - Grandparents-extensive efforts should be made to reach out to this population to offer resources or services to assist them in meeting the challenges of parenting in today's world.
  - Military Families-Partnership with military bases to ensure that these families
    have access to local resources and services should be priority, as often these
    families are under tremendous stress and lack adequate supports initially due to
    military related responsibilities.
- 3) Efforts Need to Be Undertaken to Increase the Supply of High-Quality Child Care and Pre-School in Delaware.

- Improving the Quality of Care Among Existing Providers
- Making High Quality Early Care and Education More Affordable
- 4) Opportunities Need to Be Created to Enhance the Ability of Health Care Providers to Serve as a Gateway to Services and Information.
- 5) Parenting Education and Support Needs to Be Family-focused.
- 6) Programs for Children with Special Needs Should Focus on Both the Child and the Family.
- 7) There is a Need for Initiatives to Address Maternal Depression.
  - Increased provider training on all aspects of maternal depression and appropriate community resources.
  - Provide follow-up to anyone referred for maternal depression to ensure appropriate services were obtained.
- 8) The State Medicaid Agency Should Examine How It Communicates with Hispanic Families
  - All forms and notices should be in Spanish
  - Convene a Latino panel to review and revise the Spanish-language notices & forms
- 9) Efforts are needed to Address the Shortage of Healthcare Providers for Downstate Latino Families.
  - Establish scholarship or loan programs to encourage Hispanics to pursue healthcare careers in DE.
  - Bilingual assistance to current providers who are able and willing to serve this population.

## 2.) Injury Prevention

Unintentional and intentional injuries are the leading killer of children and adults aged 1 to 44 in Delaware. The five leading causes of fatal and non-fatal injuries in this age group are: alcohol-related car crashes, poisonings, homicide, suicide and drowning. All of these injuries have risk factors that can be predicted and prevented; therefore, injuries must not be viewed as random accidents but as predictable and preventable occurrences.

Each year in Delaware, approximately 37 per 100,000 people die from unintentional injuries and approximately 18 per 100,000 people die from intentional injuries. The burden of injury to society includes not only the loss of human life, but also hospitalization and health care costs, unemployment and the reduction of quality of life for those left disabled as a result of their injuries. Specifically, in 2001, more years of potential life (years of life before the age of 65) were lost because of injuries than from any other cause, costing Delaware up to \$3 million annually.

There is much work to be done to reduce the burden of injuries in Delaware; however, throughout the past few years progress has been made, particularly in addressing unintentional injuries. As shown in Table 1 below, the rates of motor vehicle-related and poisoning-related fatal injuries have decreased, albeit not significantly. This progress is the result of several statewide efforts, including: collaboration between agencies to increase public awareness of modifiable risk behaviors; passage of legislation such as a seat belt laws and blood alcohol laws; and the modification of environmental factors to reduce risks.

Table 1 below shows the baseline and milestone for fatal injury prevention in Delaware.

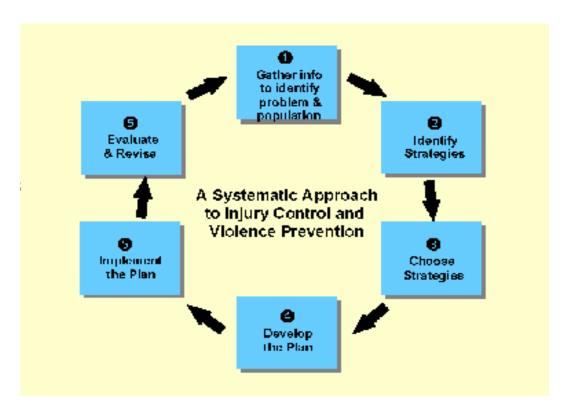
Mechanism of		rate (per	National average,	Safe Delaware 2010
Injury	100,000)	)	2001	target
	1998	2001		
Motor Vehicle	15.6	15.3	14.9*	12.8
Injury				
Fall	3.3	4.2+	5.6	2.3
Drowning	1.2	1.0	1.4	
Traumatic Brain	17.3	15.2		
Injury				
Poisoning	5.6	5.1	7.8	1.8
Fire/burn/flame	1.1	2.9+	1.3*	1.3
injury				
Homicide	5.3	4.3	7.1	4.0
Suicide	11.3	13.3+	10.8*	11
Firearm-related	8.9	9.4+	10.3	
injury				
Dog bite				

<sup>\*</sup> Indicates that the rate in Delaware is significantly higher than the national average.

# Source: Health People Delaware 2010, Delaware Vital records 2001

The development and implementation of Injury prevention activities in Delaware is based on the Injury Prevention Framework which is illustrated in the figure below.

<sup>+</sup> means Indicates that the rate in Delaware is increasing.



Source: Carolyn Runyan, University of North Carolina, Injury Prevention Program.

In 2001, a group of federal, state, non-governmental organizations and foundations came together in Delaware to form an Injury Coalition under the auspices of the Division of Public Health, Office of Emergency Medical Services. In order to give direction to this collaboration, the Injury Prevention Coalition developed a statewide Injury Prevention Strategic Plan. The purpose of this statewide strategic plan is to provide a sector-wide framework for injury prevention in Delaware. The plan addresses the nine focus areas shown in Table 1 above, which were identified by the coalition as the main causes of injury and disability in Delaware. A plan for each focus area was developed by nine work teams, which consisted of members from the Injury Prevention Coalition as well as professionals and citizens with passion for and experience in the topic area under review. These separate plans were combined to form an overall state plan for injury prevention. Five drafts out of ten were reviewed by the coalition and outside partners before the plan was finalized.

Because injuries have modifiable risk factors that can be predicted systematically, each work team used the public health approach to define and identify risk factors for their topic area. Next, teams reviewed the literature for best practices and identified implementation strategies based on effectiveness as well as the financial, social, technical and political feasibility in Delaware. Work teams identified goals, objectives and action steps to aid in demonstrating that the plan was effectively addressing the selected injury topic. Objectives are based on the Healthy Delaware 2010 statewide health promotion plan.

The Injury Prevention Program within the Delaware Office of Emergency Medical Services will coordinate the implementation of the plan. Each focus area shall be implemented through

existing injury prevention programs statewide. Each plan has process and outcome indicators which will be reviewed during quarterly meetings by the Injury Advisory Council (representatives from each focus area), and bi-annually by the Injury Prevention Coalition as a whole. The coalition is hopeful that through this plan the vision of promoting safe communities in Delaware will be realized, as measured by less fatal and none-fatal injuries, fewer risk taking behaviors, safer environment, and the reduced incidence of disability resulting from both intentional and unintentional injuries. Through effective surveillance, coalitions, training, communication and evaluation initiatives, Delawareans of all age groups will recognize and appreciate that injuries are preventable and will take charge to reduce risks. [Source: The Strategic Plan for Injury Prevention, 2004-2010.]

Each of the chapters within the strategic plan presents the individual injury prevention plans developed by each of the nine work teams as discussed above. Each individual plan contains a description of the injury problem, best practice strategies to prevent or reduce its occurrence, and the goals, objectives and action steps that the state will take to bring about this reduction. For the purpose of this needs assessment, the chapters on motor vehicle injury, traumatic brain injury, and suicides were chosen as specific mechanisms of injury to review. Of note is the active participation of the MCH Director and staff over the years leading up to the development of the strategic plan. Below is the synopsis of each as extracted form the strategic plan:

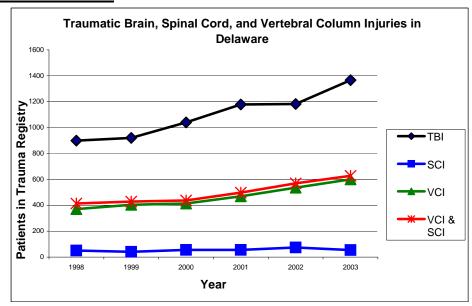
## TRAUMATIC BRAIN AND SPINAL CORD INJURY PREVENTION

#### I. STATEMENT OF THE PROBLEM

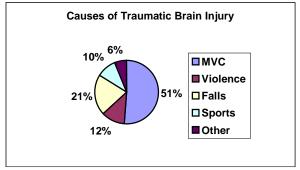
Traumatic brain injury (TBI) is the number one cause of death and disability in both children and adults. TBI is the largest acquired disabling condition of children and adolescents, with 15-24 year-olds at highest risk. In the United States, a TBI occurs every 21 seconds. Every five minutes one person will die and another will become permanently disabled due to brain injury. In 2003, 1,367 Delaware citizens sustained a TBI requiring hospitalization (Delaware Trauma System Registry). Ninety percent of TBI victims have difficulty with understanding, reasoning, learning, memory, and/or emotions. Sixty-one percent suffer from muscle weakness or uncontrollable movement, paralysis, or coordination problems. A TBI survivor's lifetime expenses for healthcare and services may reach approximately \$4 million.

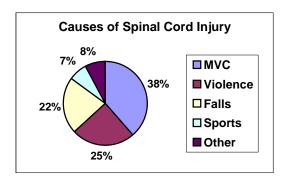
There are 11,000 new spinal cord injuries (SCI) in the United States each year. Almost half of these patients die before reaching a hospital. Current estimates are between 183,000 and 230,000 Americans are living with spinal cord injuries. More than half the people who suffer SCI are between ages 16 and 30 years. An SCI survivor's healthcare and services costs will exceed \$2 million. Lost wages and productivity can exceed \$50,000 annually. <sup>8,9</sup>

## **II. PROBLEM ANALYSIS**



Source: Delaware Trauma System Registry





Source: The Centers for Disease Control and Prevention

#### III. GOAL

To reduce the number of TBI and SCI injuries and deaths in Delaware.

#### IV. OBJECTIVES

- 1. Reduce the number of non fatal Traumatic Brain Injuries from 70 per 100, 000 in 2003 to 65 per 100,000 persons by the year 2010.
- 2. Reduce the number of TBI fatalities from 19 per 100,000 persons to 17 per 100,000 by 2010.
- 3. Increase the percentage of people discharged with severe TBI who have access to rehabilitative services by 10%. A baseline will be established in 2005 through the surveillance system.

# **V. BEST PRACTICES**

#### Surveillance

There is limited epidemiologic data on the incidence and outcome of TBI patients after discharge from hospitals. <sup>20</sup> This limits the capacity of states to estimate the number of new TBI cases and

the type of services they require. Identifying TBI cases through Hospital Discharge Data, Trauma Registries and case abstraction has been used to measure the estimated TBI services needed and to link TBI patients to services in North Carolina, Colorado and South Carolina. For effective intervention design, TBI determinants such as social economic status, personal protection use, specific age at the time of injury, drug involvement, and race and ethnicity should be collected. Also, surveillance should capture information on the availability and utilization of TBI rehabilitative services, and the outcomes of pediatric trauma services three years post TBI injury because TBI outcomes tend to subside in the first year. <sup>12</sup> All these efforts require inter-agency efforts among federal, state, legislative, statutory bodies and victims of TBI.

#### Screening

Research shows that of all high school football players in schools who have a concussion, only 26 to 28% get access to rehabilitative services. <sup>16,17</sup> Numerous studies have demonstrated that screening high risk groups for concussions can help identify children with TBI and link them to necessary rehabilitative services. <sup>17,18</sup> However this requires the development and use of sensitive and case specific screening tools. <sup>19</sup>

#### Education

Often people with a brain injury are not aware of the outcomes of the severity of their injuries and where to get help. Increasing awareness on the devastating effects of traumatic brain and spinal cord injury can increase the demand for services. In South Carolina, a care pathway for people discharged with TBI was developed in partnership between hospitals and the TBI surveillance system. Hospitals provide discharged patients with resources on TBI in the community and a TBI hotline was established to help patients call in with questions. 13 Even though this is not evaluated, similar interventions such as the poison control hotline have helped increase the utilization of rehabilitative services. Recent studies show that seating children in the front seat increases the risk of fatality by 33%; however, using a belt positioning booster instead of a seat belt reduces the risk of injury by 59%. Seventy-three of every 10,000 children in crashes are killed by air bags and one in seven sustain a severe brain injury. <sup>14</sup> Therefore, health education efforts should promote the proper use of seat belts, encourage parents to use booster seats, helmets during sports and reduce alcohol involvement when driving. Audience segmented messages should target such age groups as, children 5 to 10 years, 11 to 15 years, 15 to 22 years and adults over the age of 45. Effective education promotes the discussion of risk behaviors between parents and children.

#### **Enforcement**

States that have TBI collection and follow up systems have passed legislation. Also, legislation is necessary to promote the actions that increase personal protection, reduce alcohol intake when driving, promote stringent building codes at nursing homes, and reduce firearm related head injuries. <sup>12, 13, 14</sup>

#### **Environment/Engineering**

The impact and incidence of TBI can be reduced by modifying risks factors such as installation of guard rails at nursing homes, redesigning air bag discharge systems and replacing asphalt playground surfaces with rubber. <sup>14</sup>

## **VI. ACTION STEPS**

This plan will be implemented in partnership with public and private organizations, including the State Council for Persons with Disabilities' Brain Injury Committee, Delaware Brain Injury Association, Disabilities Law Program, Think First Delaware, and Delaware Paralyzed Veterans Association, which will help to implement planning, advocacy and funding initiatives focused on prevention of TBI and SCI. These organizations will also help with enhancement of service delivery for persons with TBI and SCI.

#### Education

- 1. Support and expand through best practice brain and spinal cord injury prevention education. Through injury surveillance and intervention evaluation, we can catalog the best practices that have working in Delaware and lessons learned from other states.
- 2. Include education about the increased risks for TBI and SCI related to alcohol and substance abuse. Support the training of educators to enable identification and development of programming for students with TBI and SCI and to promote accommodations and remediation of disability-related deficits.
- 3. Increase public awareness of the increased risk for TBI and SCI in children, especially adolescents and young adults ages 15-24.
- 4. Decrease high risk behavior in individuals with TBI.

#### **Enforcement**

- 5. Increase public awareness of laws that help to decrease injury from traffic crashes, violence, falls and sports.
- 6. Support legislative initiatives including but not limited to Dram shot liability for taverns, expanded helmet laws for motorcycles, scooters, and bicycles, regulation of electric scooters and bikes, and money following the injured person from the institute into the community.
- 7. Establish legislation that will enable the follow up of TBI cases and help to establish outcomes of care.

## **Environment/Engineering**

- 8. Assist with identification and support of changes to the environment that will help decrease the incidence of TBI and SCI such as bicycle paths and specific diving areas in public pools, playgrounds and recreational areas.
- 9. Assist with the identification and support for changes to the environment, including housing, which will improve access for those who have TBI and SCI such as ramps and physical plant modifications.
- 10. Encourage the use of and funding for access to assistive technology for TBI individuals.

# Interagency Planning, Advocacy and Funding

11. Promote governmental responsiveness to the needs of persons with TBI and SCI through the application for new planning and service grants, full implementation of the new TBI Medicaid Waiver, adoption of revised TBI eligibility standards for

- disability services, incorporation of Acquired Brain Injury-related components in disability services strategic plans and Medicaid Buy-in planning.
- 12. Interagency planning, advocacy and funding to accurately track the incidence of TBI and SCI in Delaware. Develop appropriate resources and support to help individuals and families who have suffered TBI and SCI to maintain quality of life and realize their full potential.
- 13. Delaware has developed a TBI surveillance system using the trauma registry, hospital discharge and vital statistics data. The next step will be to develop data analysis that is necessary for developing age, gender and race/ethnicity specific interventions. Case follow up will be implemented when necessary legislation is passed. This will allow for estimating unmet needs of new TBI patients who are discharged from the hospitals.

# VII. LEGISLATION

The Child Bicycle Helmet Law has been in effect in Delaware since April 1996. The law requires any person under the age of 16 to wear a properly fitted and fastened bicycle helmet, which meets or exceeds the ANSI Z90.4 bicycle helmet standard (or subsequent standard) or the Snell Memorial Foundation's 1984 Standard (or subsequent standard) for Protective Headgear for Use in Bicycling. This requirement also applies to a person who rides upon a bicycle while in a restraining seat which is attached to the bicycle or in a trailer towed by the bicycle. This requirement applies at all times when a bicycle is being operated on any property open to the public or used by the public for pedestrian and vehicular purposes. Any guardian who fails to enforce that his/her child wear a bicycle helmet shall be fined \$25 for the first offense, and \$50 for each subsequent offense. The court may dismiss all charges if presented evidence shows that a violator has purchased or obtained a bicycle helmet meeting the above-mentioned standards. The law led to the formation of the Bicycle Helmet Bank to provide free helmets to children whose families cannot afford to purchase them.

#### **Occupant Protection**

House Bill 43 – Primary Seat Belt law enacted June 30, 2003. Allows for primary enforcement of the law and requires that seat belts be used by all vehicle occupants in every seating position of the vehicle.

Senate Bill 130 – Booster Seat law enacted May 9, 2002, effective January 1, 2003. Requires children between the ages of four and seven and under 60 pounds be secured in a child safety seat or booster seat.

#### **Impaired Driving**

House Bill 111 - .08 Blood Alcohol Content (BAC) law enacted July 12, 2004, which establishes .08 as the prohibited blood alcohol concentration for driving a motor vehicle in the State of Delaware. The bill also lowered the blood-alcohol level for drunk driving from .10 to .08.

## **VIII. IMPLEMENTATION**

The Division of Aging and Adults with Physical Disabilities, in partnership with the Delaware Traumatic Brain Injury Association, shall lead the implementation of this plan.

## **IX. METHODS OF EVALUATION**

Monitoring and evaluation will be conducted by the Delaware Injury Advisory Committee in partnership with traumatic brain injury prevention programs in the state. Annual meetings will be held to evaluate program outcome and process indicators for traumatic brain injuries and spinal cord injuries. Process indicators such as TBI by cause and TBI by age/sex/race and outcome indicators such as TBI severity, TBI discharges and who accessed rehabilitative or support services in their community will be evaluated.

#### PREVENTING MOTOR VEHICLE CRASH INJURIES & DEATHS

More than 42,000 people are killed and approximately 3.3 million seriously injured on our nation's highways each year. Moreover, motor vehicle crashes are the leading cause of death and disability for Americans aged 35 and under. From 1999-2001 in Delaware, motor vehicle crashes were the number one cause of death for persons 1 to 44 years of age. In 2002, 127 persons died on Delaware roadways and 9,960 individuals were injured. Of those killed, 36% (46) of the deaths were alcohol-related and 64% (64) were not wearing a seat belt. 57% (67) of the 117 fatal crashes resulted from aggressive driving behaviors. Of the 9,960 crash-related injuries in Delaware in 2002, 1,035 were alcohol-related. The economic impact and emotional toll of traffic crashes are staggering. It is estimated that motor vehicle crashes cost America \$231 billion annually, an estimated \$7 billion in Delaware alone.

## II. PROBLEM ANAYLSIS

#### **Occupant Protection**

Based on the Statewide Observational Seat Belt Use Survey conducted by the Office of Highway Safety in June 2004, Delaware's seat belt use rate is 82%, up from 75% in 2003. The current national seat belt use rate is 80%. In 2003, 55% (62 of 113) of those killed in motor vehicle crashes on Delaware roadways were not wearing seat belts.

#### Delaware Seat Belt Use Data

	1996	1997	1998	1999	2000	2001	2002	2003	2004
Use rate	62%	59%	62%	64%	66%	67%	71%	75%	82%

## **Delaware Motor Vehicle Occupant Fatality Data and Seat Belt Use**

	1996	1997	1998	1999	2000	2001	2002	2003
Fatalities	85	123	89	82	100	108	100	113
% not using seat	49%	65%	62%	68%	72%	64%	64%	55%
belts	41 of 85	80 of 123	55 of 89	56 of 82	72 of 100	69 of 108	64 of 100	62 of 113

#### **Impaired Driving**

In 2003, 38% (52 of 136) of the fatal crashes in Delaware were alcohol-related and 37% (54 of 145) of the traffic fatalities were alcohol-related. Nationally, 2002 crash data reveals that 41% (17,419) of the 42,815 traffic fatalities on our nation's roadways were alcohol-related. In Delaware, most alcohol-related crashes occur between Friday and Sunday, between the hours of 8 p.m. and 4 a.m. It can also be noted that the majority of these crashes involve males between the ages of 22 and 54.

**Delaware – Historical Alcohol Involvement in Fatalities** 

	1996	1997	1998	1999	2000	2001	2002	2003
Fatalities	120	148	115	104	130	139	127	145
% Alcohol	40%	43%	37%	38%	45%	42%	36%	37%
	48 of 120	63 of 148	43 of 115	40 of 104	59 of 130	58 of 139	46 of 127	54 of 145

## **Aggressive Driving**

In 2003, the three primary contributing circumstances for all types of aggressive driving-related crashes were "failure to yield the right of way, speeding, and following too closely". Since 1995, the percentage of all crashes resulting from aggressive driving behaviors has remained around 43%, yet the percentage of fatal crashes resulting from aggressive driving behaviors has increased from a low of 38% (46 of 121) in 2000 to a high of 57% (67 of 117) in 2002.

Delaware – Percentage of fatal crashes resulting from aggressive driving behavior

	1996	1997	1998	1999	2000	2001	2002	2003
Total fatal crashes	109	125	107	94	121	118	117	136
Aggressive driving related	51	53	53	51	46	60	67	70
Percentage	47%	42%	50%	54%	38%	50%	57%	51%

#### III. GOAL

The overall goal of Healthy Delaware 2010 is to reduce fatalities resulting from motor vehicle crashes from 16 per 100,000 population to 12 per 100,000 population. Accordingly, the goal for 2005 is to reduce the current death rate to 14 per 100,000 population.

#### IV. OBJECTIVES

1. Conduct occupant protection enforcement initiatives, education programs and public awareness efforts aimed at increasing the statewide seat belt use rate from 75% in 2003 to 83% in 2005.

- 2. Conduct impaired driving enforcement initiatives, coordinate public awareness efforts, provide alcohol treatment services for DUI offenders and work to improve the DUI adjudication process aimed at reducing alcohol-related fatalities from 37% (54 of 145) in 2003 to 34% in 2005.
- 3. Conduct enforcement initiatives, education programs and public awareness efforts aimed at reducing fatal crashes resulting from aggressive driving behaviors from 51% (70 of 136) in 2003 to 48% in 2005.
- 4. Implement a statewide-integrated crash data collection system, which will allow for the comprehensive analysis of crash data including pre-hospital, fatality, injury, location, time of day, day of week, contributing circumstances and adjudication information. This data collection system will help to ensure effective policy development, program planning and resource allocation.

#### V. ACTION STEPS

## <u>Increase Passenger Restraint Use</u>

**Action Step 1:** Support high visibility enforcement of occupant protection laws coupled with educational programming and public awareness efforts.

Action Step 2: Educate law enforcement officers, judges, prosecutors, emergency medical services personnel, employers, driver trainers, insurers and others about the effectiveness of safety restraints and the importance of consistently using safety restraints.

Action Step 3: Support efforts to increase public awareness about the importance of consistently using safety restraints.

**Action Step 4:** Support community-based education and training about child passenger safety issues. Continue to offer training on correct the use and installation of child safety seats.

**Action Step 5:** Work with law enforcement and emergency medical services to improve crash data collection, including safety restraint use data.

# Decrease Prevalence of Impaired Driving

**Action Step 1:** Support high visibility enforcement of impaired driving laws coupled with educational programming and public awareness efforts.

**Action Step 2:** Support comprehensive public awareness programs aimed at educating the public about the dangers of drinking and driving.

Action Step 3: Advocate for passage of strong and effective impaired driving laws.

**Action Step 4:** Support implementation of training programs specific to impaired driving issues for law enforcement, prosecutors and legislatures.

# Decrease Prevalence of Aggressive Driving

Action Step 1: Support high visibility enforcement of aggressive driving laws coupled with educational programming and public awareness efforts.

Action Step 2: Support efforts to increase public awareness about the dangers associated with aggressive driving. Support efforts to increase public awareness about the State's graduated driver licensing law.

**Action Step 3:** Encourage highway officials to identify and implement programs that will utilize new technologies aimed at decreasing aggressive driving.

## VI. LEGISLATION

## Occupant Protection

- House Bill 43 Primary Seat Belt law enacted June 30, 2003. Allows for primary enforcement of the law and requires seat belt use by all vehicle occupants in every seating position of the vehicle.
- Senate Bill 130 Booster Seat law enacted May 9, 2002, effective January 1, 2003. Requires children between the ages of 4 and 7 and under 60 pounds to be secured in a child safety seat or booster seat.

## **Impaired Driving**

 House Bill 111 - .08 Blood Alcohol Content (BAC) law enacted July 12, 2004. Establishes .08 as the prohibited blood alcohol concentration for driving a motor vehicle in the State of Delaware. Lowers the blood-alcohol level for drunk driving from .10 to .08.

## **Aggressive Driving**

• House Bill 364 – Aggressive driving law enacted June 30, 1999, effective July 22, 1999. This bill created a new offense called aggressive driving that is based on a combination of unsafe and unlawful driving actions committed by a motorist.

## VI. IMPLEMENTATION

The Delaware Office of Highway Safety (OHS) shall lead in the implementation of this plan in partnership with Delaware Safe Kids Coalition and the CODES project. Many of the actions listed in this plan are integrated into the OHS injury prevention plan.

## VII. METHODS OF EVALUATION

Monitoring and evaluation will be conducted by the Delaware Injury Advisory Committee in partnership with motor vehicle injury prevention programs in the state. Annual meetings will be held to evaluate program outcome and process indicators such as motor vehicle injuries and deaths, impaired driving and occupant protection. The Office of Highway Safety in partnership with the Delaware CODES project and the Injury Prevention Data Review Committee shall lead the evaluation of this plan. Process indicators such as hospitalizations, seat belt use, helmet use, booster seat use, cost of hospitalizations, and alcohol involvement in crashes shall be reviewed. Outcome indicators for review shall include fatal crashes, motor crash disabilities and the effectiveness of specific interventions.

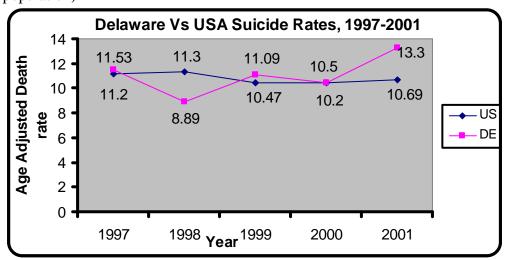
## SUICIDE PREVENTION

#### I. STATEMENT OF THE PROBLEM

Suicide is a major public health problem in Delaware with nine suicide deaths monthly. In 2001, Delaware ranked 16<sup>th</sup> in the nation for suicide deaths.<sup>i</sup> More people die in Delaware by suicide than by homicide. The suicide rate has increased from 11.09 per 100,000 in 1998 to 13.30 per 100,000 population in 2001. This is far above the national average of 10.7 deaths per 100,000 in 2001<sup>13</sup>. In 1999-2000, suicide was the 11<sup>th</sup> leading cause of death in Delaware while homicide ranked 16<sup>th</sup>.<sup>ii</sup> In this same period, suicide was the 2nd leading cause of death in the age group 15-24, and 4<sup>th</sup> in the age group 25-44, resulting in three times more years of life lost than homicide<sup>6</sup>. One in five high school students has seriously considered suicide, with one in ten making attempt<sup>12</sup>.

#### II. PROBLEM ANALYSIS

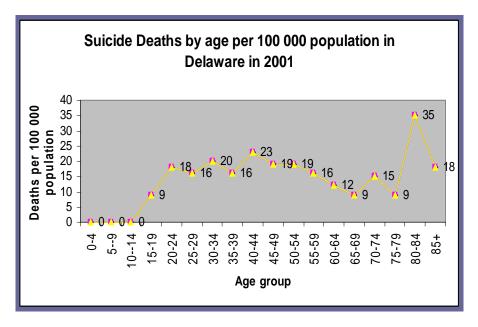
Figure 1 below shows the increase in suicides in Delaware between 1999 and 2001. The number of suicides has increased from 82 (11.1/100,000 population) in 1999 to 108 (13.3/100,000 population) in 2001.



Source: CDC WISQARS: Injury Mortality 2001

In 2001, suicide was the 11<sup>th</sup> leading cause of death in the United States; homicide was the 13<sup>th</sup> leading cause of death in the United States.<sup>iii</sup> Firearms are currently the most often utilized method of suicide.<sup>iv</sup> Daily, about one person gets hospitalized for an attempted suicide in Delaware. Males complete suicide at a rate 4 times greater than females.<sup>v</sup> In 1999-2001, suicide was the third leading cause of death in Delaware in the age group 5 to 14, the second leading cause in the age group 15 to 24, and the fourth leading cause among the age group 25 to 44.<sup>9</sup>

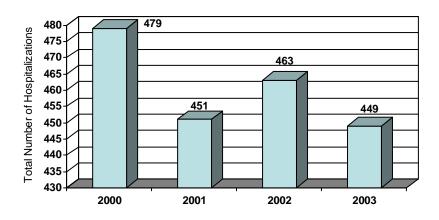
72



Source: Delaware Office of Vital Statistics, 2001

People who are 15 to 44 year olds and adults over 75 are the populations who have the greatest risk of committing suicide in Delaware.

Figure 2. Hospitalizations for Suicide Attempts in Delaware, 2000-2003



Data Source: Delaware Hospital Discharge Data from 2000 to 2003

The ranges used for the suicide attempts include E-Codes from E950 to E959 in the E-Code field.

Psychological autopsy studies reflect that more than 90% of completed suicides had one or more mental disorders. <sup>10</sup> In Delaware the number of youths reporting suicidal ideation and attempts showed a decrease between 1999 and 2003 as shown in Figure 3 below. However, the percentage of youths reporting suicidal attempts has increased from 6 in 1999 to 8 in

73

2003. There are an estimated 8 to 25 attempted suicides for each suicide death; more women than men report a history of attempted suicide with a ratio of 3:1.<sup>vi</sup>

Figure 3: Suicidal Behavior Among Delaware Youths 1999-2003

Source: Youth Behavior Factor Surveillance System

Group diagnoses for particular risks include: those with depression, schizophrenia, chemical dependency, and panic disorder. vii

## III. GOAL

Promote awareness that suicide is a preventable public health problem and enhance behavioral and social changes necessary to reduce suicidal ideation and attempts.

## IV. OBJECTIVES

- 1. By 2010 the number of youths considering suicide will be reduced from 27% in 2001 to 15%.
- 2. By 2010 the number of suicidal attempted suicides will be reduced from 7.1% in 2001 to 5%
- 3. By 2010 the suicide death rate will be reduced from 13.30 per 100,000 population in 2001 to 10.
- 4. By 2010 the proportion of youths considering suicide who report receiving counseling or medical intervention shall be increased to 70%. The baseline will be established from using the 2006 Youth Risk Behavior Factor Survey.

## V. BEST PRACTICES Literature suggests that the following interventions are effective.

# 1. Partnerships based approach to suicide prevention.

Involving the community in recognizing and counseling people with suicide ideation or attempts can increase the chances of reducing suicide attempts. For example, a program called Gatekeepers has been implemented in Colorado to help adults in schools and communities who come into contact with suicidal youths to respond promptly and appropriately. This project is built on the premise that youths will only disclose secrets to people they are comfortable with and these people will be friends who are non-judgmental. Results from such studies have

demonstrated that participants in specific gatekeeper training programs have enhanced their readiness to intervene by increasing their comfort, competence and confidence in helping people at risk, and such participants generally retain the skills they were taught<sup>14</sup>. Gatekeepers must be aware of common predictors of suicide such as major depression, affective disorder, previous suicide ideation/attempts, isolation, cognitive rigidity, elderly white males, family history of suicide, occupational/financial problems, acute life stressors, marital problems and physical illness<sup>21</sup>. Suicide prevention education should focus on males because they are less likely to report attempted suicide but are more likely to complete suicide <sup>20</sup>.

Several studies show that 46-76% of older people who committed suicide saw a health care provider within the last 30 days of death<sup>5</sup>. It is not uncommon that healthcare workers see suicidal behavior in the elderly and women in post menopause age as normal<sup>3, 4</sup>. A Japanese study showed that a community-based screening for depression in the elderly, followed up by a mental health counselor and health education resulted in a significant reduction in suicide among the elderly <sup>23</sup>. Mental health education for religious organizations, day care providers, nursing schools and maternal health providers should be encouraged as part of promoting a continuity of care to suicide survivors or high risk groups<sup>17</sup>. This is because people with a history of suicide are more likely to repeat suicide <sup>4</sup>.

## 2. Promote efforts to reduce access to lethal means and methods of self-harm.

Research shows that restricting access to locally prevalent lethal means of suicide is an effective suicide strategy<sup>3, 21</sup>. Most suicides are impulsive—as such, any easy access to firearm or poison increases the risk of suicide by 75% and reduces survival by 80%<sup>4</sup>. Reducing access to firearms is feasible in Delaware with much health education, enforcement of regulations, and increased partnerships among the justice department, the Medical Examiner's Office, the State Police, schools, community organizations, mental health and hospital organizations. In Delaware, gun safety education is promoted in schools by the Risk Watch program. A study in Baltimore showed that gun-related suicides and injuries went down with increased community enforcement and punishment for gun violations<sup>20</sup>. Fear of being cited for gun violation is associated with reduced gun suicide<sup>22</sup>. The Delaware Project Safe Neighborhoods has stepped up gun violation monitoring with a view to increase gun safety. Indictments increased by 340% between 2001 and 2003. Since 8-10% of suicide attempters are alcoholics, health awareness and restrictions must be increased among alcoholics<sup>20</sup>.

#### 3. Increase access to services

Crisis hotlines are widely encouraged by suicide prevention programs. A study by Miller (1984) showed a 55% reduction in suicide rates with the introduction of a crisis hotline<sup>24</sup>. However, other studies caution that youths tend to opt for help from peers rather than professionals when in need of help<sup>29</sup>. Therefore, innovations that attract adolescents such as email and internet chat rooms should be explored<sup>28</sup>. Establishing care pathways for patients between institutions such as mental health, correction facilities and crisis hotlines is essential for ensuring a continuum of care for potential victims of suicide. Also services should be provided to friends of individuals who commit suicide because they are at risk of developing depression, post traumatic stress disorder and complicated grief reactions<sup>31</sup>. In Delaware amendments have been made to the

Violent Crimes Compensation Board to support mental health treatment for children with psychological and behavior antecedents of suicide through the Child Advocacy Center.

While health education is essential for increasing suicide awareness, current evidence suggests that an increase in suicide follows suicide stories in the media—"contagion effect"<sup>29</sup>. Therefore, education should describe what should be avoided and where to get help<sup>30</sup>. Such an education strategy was associated with a 73% reduction in youth suicide in Vermont <sup>25</sup>.

# 4. Screening and treatment of suicide

Screening of people for depression not only provides a proxy for estimating the anticipated suicide problem, but it also indicates those needing interventions. The Youth Behavior Risk Survey provides an estimate of suicidal attempts, but this data is not school specific and therefore cannot be used to identify which youths require counseling. Several states have adopted a three-stage direct youth screening strategy. First, teens complete the Columbian Teen Screening questionnaire. The results are reviewed by a trained counselor who then recommends that students with high scores take a computerized screening test. Computer results are then reviewed by a physician who then recommends an appropriate therapy <sup>16</sup>. School nurses, teachers and caregivers at nursing homes should be trained in identifying suicidal behavior and clear referral protocols should be established.

Medical personnel can help to identify and treat people who are at risk of committing suicide<sup>22</sup>. Common predictable markers of suicide in adults include major depressive illness or affective disorder, drug/alcohol abuse, prior suicide attempts/ideation/talks, isolation, cognitive rigidity, history of suicide in the family and social/family stress<sup>17-20</sup>. A recent review of several studies showed that the main risk factors for suicide include non-intact family (61%), conflict with parent (51%), legal discipline (31%), psychiatric disorder (95%), psychiatric morbidity (81%), mood disorder (76%), major depression (54%) and substance abuse (62%). Recent studies have shown that addiction and withdrawal from illicit drugs increase the risk for suicide attempts<sup>28, 32</sup>. The Food and Drug Administration has recently issued warnings that the unsupervised intake of antidepressants by children could increase the risk of depression<sup>33</sup>. An Australian study that promoted early screening of suicide in children and followup by a suicide intervention counselor reduced the suicide hospitalizations from 11% to 4 %<sup>26</sup>. Obstetricians can contribute to the reduction in post-partum depression and suicide by offering screening and counseling services to pregnant women<sup>27</sup>. Model skill based training includes, health education on risk and protective factors, mentoring, recreation and physical education, psychological and pharmacotherapy, family and community integration and occupation opportunity services <sup>28-30</sup>.

## 5. Skills training and rehabilitation.

Since most school-based suicide prevention education strategies have not been known to reduce suicidal risk behaviors<sup>34</sup>, recent studies recommend skills-focused education which incorporate coping, problem-solving and cognitive skills into school-community based programs<sup>15</sup>. Such skills-based interventions must be introduced at an early age especially in children from stress ridden non-intact families<sup>28</sup>.

# VI. ACTION STEPS/ INJURY PREVENTION

Actions to meet each objective are itemized as, Objective number and Action number. For example, 1.1 means Objective 1, action number 1.

Objective 1.1: Develop a public information campaign designed to increase public knowledge of the importance of suicide prevention. The Child Death Review Commission recommends having a Crisis Hotline on all school computers for students to access anytime.

Objective 1.2: Develop strategies to reduce the stigma associated with being a consumer of mental health, substance abuse and suicide preventions services.

Objective 2.1: Increase the proportion of school districts, private school associations, colleges, and universities with evidence-based programs designed to address serious young adult distress and prevent suicide.

Objective 2.2: Increase the proportion of organizations (e.g. businesses, senior centers, community centers, Girl Scouts, etc.) that ensure the availability of evidence-based prevention strategies for suicide prevention.

Objective 2.3: Promote screening for depression, substance abuse and suicide risk by health professionals.

Objective 3.1: Expose a proportion of households to public information campaign(s) designed to reduce the accessibility of lethal means, including firearms in the home. Project Safe Neighborhoods, a Delaware subsidiary of Operation Disarm Gun, has increased the number of federal firearm indictments by 340% between 2001 and 2004<sup>19</sup>. Continue gun safety education in schools through Risk Watch.

Objective 4.1: Develop guidelines for schools on appropriate linkages with mental health and substance abuse treatment services and implement these guidelines in all schools.

Objective 4.2: Increase the proportion of private and public sector organizations that offer assessments of mental heath and substance abuse problems and access to care. Also institute crisis hotlines on school computers and wellness clinics.

## VII. LEGISLATION

The Garrett Lee Smith Memorial Act (S. 2634), which passed both the U.S. House of Representatives and the U.S. Senate on September 9, 2004, and signed into law by the President in October, amends the Public Health Act and authorizes \$82 million in grant money over a three-year period to states, Indian tribes and colleges and universities for the development of youth suicide prevention and intervention programs. The bill calls for early screening programs to identify mental illness in children and provide treatment referrals, training for community child-care professionals and the authorization to states and other eligible entities. The Act will

bring parity to federal funding for public health issues by more than doubling the amount of money that the federal government allocates to suicide prevention.<sup>18</sup>

## VIII. IMPLEMENTATION

Delaware's Mental Health Association, in partnership with the Division of Substance Abuse and Mental Health, will lead in the implementation of statewide suicide prevention efforts.

#### IX. METHODS OF EVALUATION

The lead agency shall call meetings with leaders of partner organizations to review process indicators such as active partners, resource use or availability, access to counseling services and utilization of counseling or mental health services. Annually, outcome indicators such as suicide rates, attempted suicides, suicide ideation and means of suicide shall be reviewed with the help of the Data Review Committee.

# Lifecycle #2 – Needs of the Child and Adolescent Population Service Area #3: Mental/Behavioral Health Needs

- Behavioral health needs were characterized and documented in the 1999 Delaware Institute for Medical Education and Research (DIMER) reports as inadequate. DIMER found a "severe shortage" of mental health practitioners in Sussex County. However, Sussex County lost its federal Mental Health Shortage Designation Area (HPSA) in 1998. Data analysis is underway at DPH to determine if HPSA designation can be reinstated.
- Based on interviews and a review of limited Sussex County data available from the Division of Substance Abuse and Mental Health (DSAMH):
  - Ambulatory chemical dependency and substance abuse services (CD/SA) appear to be insufficient. Capacity has increased over the past few years to include more outpatient providers. There is a plan to develop a methadone program this year.
  - Child and adolescent services are insufficient.
  - Specialty geriatric mental health services are virtually non-existent.
  - SBHC staff report significant access problems to mental health services for children and adolescents:
    - 1. No formal process is available for adolescent behavioral health referrals or for linkages between primary care and behavioral health resources.
    - 2. There are 0.5 FTE child psychiatrists in eastern Sussex County.
    - 3. Sussex County has no pediatric or adolescent behavioral health inpatient units or hospital services.
    - 4. Knowledge of, and linkages between, resources (communication) in the child and adolescent population are lacking.
    - 5. Transportation/data from schools confirm that access for adolescents is a real problem.
    - 6. Although small in absolute numbers, needs data reveal high suicide rates among the teen population.

- Hospital personnel report a significant proportion of emergency room use is directly related to behavioral health needs and that providers do not feel they can provide optimal care for these problems in the emergency room setting. Sussex County has no involuntary admission capacity. Most involuntary admissions are taken to St. Jones Center in Kent for acute hospitalizations, although this capacity is limited and some may be taken to NCC acute hospitals if St. Jones doesn't have any beds. Individuals are transported to these hospitals by "peace officers" as defined in State code (transported in police cars by on duty officers).
  - Managed care organizations as well as other payers are emphasizing outpatient treatment
  - Credentialing limitations limit use of non-physician providers
- There are cultural issues driving a hesitancy to use mental health and substance abuse services for many Sussex County individuals. Leadership, planning, and communication (for targeted populations) needs to be improved, especially addressing dual diagnosis; isolation and depressions; and stigma associated with seeking mental health care.
- There is a stigma about mental health and mental health treatments that must be addressed. Stigma against mental illness and its treatment is found throughout the country and for all age groups.

## Service Area #3: Mental/Behavioral Health Resources

# Summary of Findings: Mental/Behavioral Health

- <u>Awareness</u>: Geriatric population barriers are cultural and related to the stigma associated with mental health treatment. Differences in awareness may be related to geography (closer to hospitals = higher awareness).
- <u>Access</u>: Sussex in not classified as a HPSA for mental health care. One part-time child psychiatrist in Lewes is the only one in the county and is involved mostly in crisis work. Significant barriers to access to specialized child, adolescent and geriatric providers was consistently reported. Transportation from schools complicates access for adolescents.
- <u>Direct service</u>: A significant portion of emergency room use is directly related to behavioral health needs. Reimbursement levels for providers are well below average and may impact access.
- <u>Referral</u>: No formal process for adolescent referral or linkages between resources. For the adult population, many know what is needed, but it may take multiple calls to arrange for services.
- Monitoring: External outcomes measurement is beginning (United Way, Managed Care, Delaware Health and Social Services (DHSS)/Division of Substance Abuse and Mental Health (DSAMH). Burden of "non-institutionalized" mental health is not well understood at the county level. Mental Health Parity Law passed in 1999 and substance abuse coverage was added to the law in 2001. Money was never appropriated by the legislature to implement the bill (as mandated in the bill's language).
- <u>Infrastructure</u>: Sussex County has no involuntary admission capacity. Transportation of involuntary patients in inadequate. Licensing and health plan credentialing regulations problematic for non-physician providers. Inadequate chemical dependency/substance abuse services.

- <u>Leadership</u>: The Delaware Health Care Commission's Mental Health Issues committee will issue a draft report Spring 2004. This Mental Health Issues committee has four subcommittees: Data Gathering; Treatment Protocols; Training and Employer Education; and Public Awareness.
- <u>Planning</u>: Need more focus on outpatient care. Looking more at parity in mental health benefits for adult population. More focus on geriatric population, especially in the areas of dual diagnosis, isolation, mental health stigma.
- <u>Communication</u>: Linkages among providers serving adolescent population are lacking. Interagency Council is helping increase communication.
- While meaningful county specific data is lacking in younger childhood needs, extrapolation of state level data suggests that asthma and childhood obesity are areas that may require attention.
- In Delaware, asthma affects almost 14,000 children.
- Nationally, childhood obesity has reached epidemic proportions.
- Of the state's three counties, Sussex has the highest overall injury death rate at 39.8 per 100,000<sup>11</sup>. This figure is 36 percent higher than the Kent County rate and over 79 percent higher than the New Castle County rate. The high motor vehicle-related death rate in Sussex County contributes to the overall increased injury death rate for the county and the entire state. See Table 8.

Table 8
Leading Causes of Injury Deaths by County

Kent County, 1979-1998, Ages 0-19				
Manner of Injury/Poisoning	Number	Percent	Rate <sup>12</sup>	
Motor Vehicle Traffic	105	51.5	15.1	
Fire/Burn	22	10.8	3.2	
Drowning/Submersion	20	9.8	2.9	
Firearm	17	8.3	2.4	
Suffocation	11	5.4	1.6	
All Other Injuries	29	14.2	4.2	
TOTAL	204	100.0	29.3	

Sussex County, 1979-1998, Ages 0-19					
Manner of Injury/Poisoning	Number	Percent	Rate		
Motor Vehicle Traffic	139	56.0	22.3		
Fire/Burn	25	10.1	4.0		
Drowning/Submersion	24	9.7	3.9		
Firearm	20	8.1	3.2		
Suffocation	11	4.4	1.8		
All Other Injuries	29	11.7	4.7		
TOTAL	248	100	39.8		

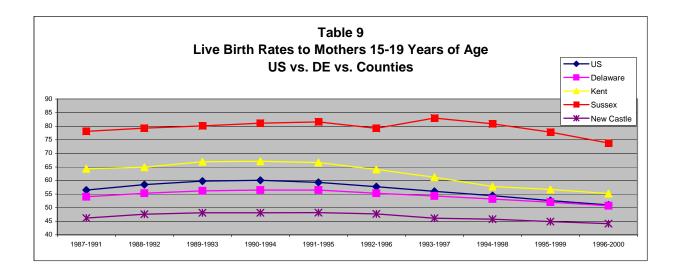
- As articulated in Delaware's Maternal and Child Health Block Grant application, the following needs are apparent in Sussex County for special needs children:
  - 1. Insufficient services for occupational therapy (OT), physical therapy (PT) and speech therapy needs.
  - 2. Quality childcare needs for the population is insufficient.
  - 3. Care coordination is insufficient for children >3 with special needs.
  - 4. Culturally compatible specialty care access is insufficient.
  - 5. Not enough service providers for the socio-emotional needs of young children and even less preventative services available.
- The Sussex County live birth rate to mothers 15-19 years of age is 73.8, which is higher than the nation (51.0); Delaware (50.7); New Castle County (44.1); and Kent County (55.2)<sup>13</sup>. See Table 9.

-

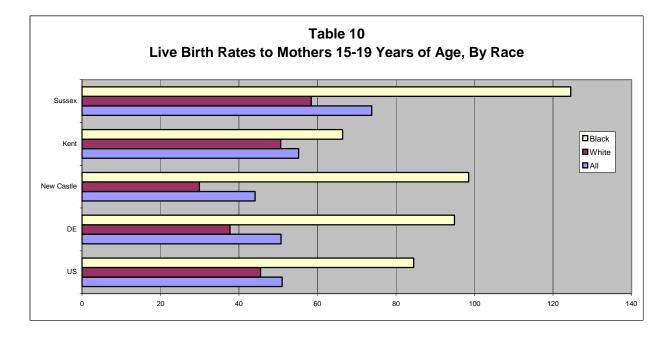
<sup>&</sup>lt;sup>11</sup> Delaware Health and Social Services, Division of Public Health, Childhood Injury in Delaware, 2001

<sup>&</sup>lt;sup>12</sup> Rate per 100,000

Teen live birth rates in several census tracts (Bridgeville, Selbyville and Laurel) stand out as extraordinarily high.



For White teen mothers, the Sussex County rate is 58.4, which is higher than the nation (45.5); Delaware (37.7); New Castle County (29.9); and Kent County (50.6)<sup>14</sup>. For Black teen mothers, the Sussex County rate is 124.5, which is higher than the nation (84.5); Delaware (94.9); New Castle County (98.5); and Kent County (66.4)<sup>15</sup>. See Table 10.



 <sup>&</sup>lt;sup>13</sup> Table C-6, *Delaware Vital Statistics Annual Report*, 2000, page 64.
 <sup>14</sup> Table C-7, *Delaware Vital Statistics Annual Report*, 2000, page 65.

<sup>&</sup>lt;sup>15</sup> Table C-8, *Delaware Vital Statistics Annual Report*, 2000, page 66.

- All high schools in Sussex County have a School Based Health Center (SBHC); all but one in Kent County has a SBHC.
- Based on interviews and SBHC data, teen primary health care needs are characterized as "largely unmet."
- Teen mental/behavioral health needs are also not adequately met due, in part, to a lack of providers serving this population. In addition, for both primary care and mental health needs, transportation is inadequate and conflicts with access and confidentiality needs.
- Self-reported substance use in older Sussex County adolescents exceeds state rates. The need for improvement is particularly apparent for the increase in use reported between grades 8 and 11, which greatly exceed the state. The Kent County rates are lower than the state in the area of marijuana use<sup>16</sup>. See Table 11.

Table 11 8 <sup>th</sup> v 11 <sup>th</sup> Grade Self Reported Substance Use			
	Grade 8	Grade 11 %	
Cigarettes		1	
Sussex	13	24	
Kent	12	20	
Delaware	12	20	
Alcohol			
Sussex	25	49	
Kent	25	43	
Delaware	24	43	
Marijuana			
Sussex	13	28	
Kent	10	21	
Delaware	14	25	

# B. Program Capacity by Pyramid Levels

# 1. Direct Care Services and Enabling Services

# **Financial Access**

Impact Of Medicaid And Managed Care

The MCHBG continues to support the provision of direct child health services (EPSDT, immunizations, counseling, TB screening, lead screening and health education). These services are provided primarily to the uninsured, under-insured and a small number of Medicaid clients when referred by their primary care physician. However, with the implementation of Medicaid managed care and the duPont Pediatric Clinics, there is less of a need for DPH to provide these direct services. There are 12 of these Clinics situated throughout the state. Seven are in New Castle County. The other four are in Dover, Milford, Seaford and Georgetown. The hospital

<sup>&</sup>lt;sup>16</sup> Center for Drug and Alcohol Studies, University of Delaware, 2002

served over 80,000 outpatient clients at the hospital and 120,000 in the primary care sites. See below for map of specific locations.

# Impact of SCHIP

The Delaware Healthy Children Program began on January 1, 1999. It is being administered by the Medicaid Office, Division of Social Services, Delaware Health and Social Services. Coverage includes well visits for babies and children, immunizations, prescription drugs and vision care and other routine services. It also includes services for children with special health care needs such as therapies and home health where medically necessary. Non-emergency transportation, dental benefits, and eyeglasses are not covered under the program. There is a nominal monthly premium of 10, 15, or 25 dollars depending upon income.

Recent analysis shows that enrollment in this program has slowed down. The point between the initial application and the time when an individual picks her provider and pays is a critical one and some individuals are not following through to enrollment. Those who have been asked to pay a premium of \$10.00 seem to be having greater difficulty in making payments. This situation may be a result of the "buy-in" not being there; eligible families believing that they cannot afford the expense; or for families cycling on and off between coverage by the Delaware Healthy Children Program and Medicaid, causing differing payment policies and resulting confusion.

The Division of Public Health has been awarded a Robert Wood Johnson Covering Kids Project grant to coordinate and enhance outreach efforts connected with implementation of this program. It has been estimated that 10,500 uninsured children may be eligible for the program. By March 2000, 2,590 children had been enrolled.

# **Availability of Prevention and Primary Care Services Shortages of Health Care Providers**

Oral health: There is a severe shortage of dentists in Sussex County and a less than optimal situation in Kent County and in some sections of the city of Wilmington. Throughout the state, most dentists serve pediatric patients. About 25% of dentists will serve a child under three years of age. However, a recent report by the Delaware Health Care Commission, Dental Care Access Improvement Committee Report and Recommendations to the Delaware Health Care Commission noted that while there has been some progress made, there are some issues that still need to be addressed. Some of these as they particularly relate to children are:

- School nurses report severe access problems particularly for those from low-income families.
- Although Public Health has hired additional hygienists, wait time for a clinic visit is extremely long (after initial diagnosis 5 to 6 months) and used to fix existing problems rather than for preventative care.
- The number of Medicaid eligible children being served is much too low because of the overall dental access problems. These problems have prevented Delaware from including dental services in its Delaware Healthy Children Program.

Most dental care provided to Medicaid recipients under the age of 21 has been provided in the Public Health dental clinics. Four sites in Kent and Sussex Counties employ two full-time dentists, contractual dentists equal to one full time equivalent, and three part-time hygienists. The

four sites in New Castle County employ four full-time dentists. As the Delaware Health Care Commission reports, if the clinics served the whole population that would mean a ratio of one dentist to 5,000 patients. An estimate of Medicaid eligible children served at the clinics is 29% in New Castle County, 18% in Kent County, and 25% in Sussex County. Although more private practice dentists are participating in Medicaid, about 50%, in 1998 Medicaid patients, including adults were served by only 3.6% of general private practice physicians. An estimate of children served by private practice dentists is less than 3%.

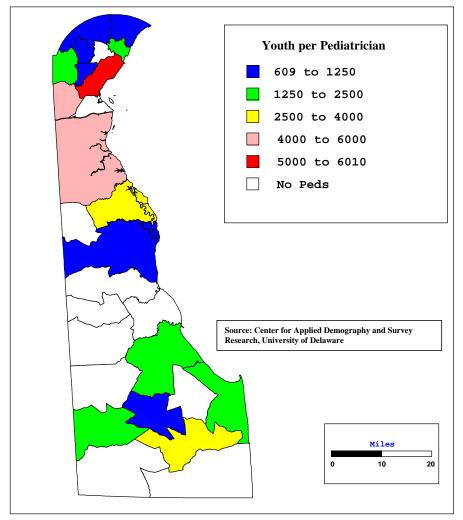
The Dental Care Access Improvement Committee recommended the following strategies to improve dental care in Delaware:

- Marketing the benefits of practicing in Delaware with consideration given to racial and cultural composition of the targeted population
- Education loan repayments or other financial assistance for capital costs for dentists establishing a practice in an underserved area
- Implementing a reciprocity program offering provisional licensure for dentists serving in underserved areas instead of a one-year general practice residency requirement
- Implementing a preceptorship program available to dentists who are Board eligible in Delaware if they practice under direct supervision of a licensed dentist in an underserved area
- Licensure changes to make it easier to attract qualified dentists and hygienists such as allowing dental hygienists to work in schools, mobile health vans and other settings under state dental director supervision and reducing practice experience required.

If dental services for Medicaid eligible children are lacking, it is expected that for children whose families are uninsured or underinsured, accessibility would be worse. This data was not available but it is interesting to note that an average of about 7.5% of general dentists' gross fees was not reimbursed as a result of charity care. According to the University of Delaware's Dentists in Delaware-1998 report about 40% of dentists provide some charity care outside of the offices. Proportions providing charity care are less in Kent and Sussex Counties but this probably reflects their greater workload.

Primary Care Physicians in Delaware reported that pediatricians are almost 20% of the total primary care physician population. As with OB-GYNs, they are generally located nearer hospitals. The most underserved areas are southern Kent County and southern Sussex County. Georgetown in Sussex County, Dover in Kent and northern and western New Castle County has the highest rates of pediatricians per the number of youth. One problem that has been noted is the low number of Hispanic pediatricians. Survey responses showed no Hispanic pediatricians in either Kent or Sussex counties. However, there was a surprising number, 48%, who could speak Spanish, most located in New Castle County. See below map for distribution of pediatricians.

# Number of Youth (0-19) per Pediatrician by Census County Division



Gaps in mental health for young children and adolescents: Both existing data and perceptions by providers and consumers point to gaps in mental health services for children. A study completed under the auspices of the Disabilities Planning Council identified several gaps in mental health services for adolescents. They are: 1) too few adequate alternatives for special living arrangements such as structured residential settings; 2) not enough vocational rehabilitation and continuing education opportunities; and, 3) not enough one-on-one support for severely mentally ill or depressed adolescents. This study also noted that there are not enough trained therapists for very young children.

As already stated, hospital discharge data for 10 to 14 year old children shows that childhood mental disorders are the number one cause (9%) for hospitalizations for this age group. Other

mental health related diagnoses include: depression (ranked 2nd at 8%), psychoses (ranked 3rd at 8%), neuroses except depressive (ranked 8th at 3%). Black children 10-14 are not hospitalized as frequently for mental disorders as the rest of the population. However, childhood mental disorders are ranked 2nd at 6%, depression (ranked 3rd at 6%), psychoses (ranked 5th at 5%). For teens 15 to 19, discharges related to birth are the most prevalent rate. After birth, however, psychoses ranks 3rd (6%), depression ranks 4th (4%) and childhood mental disorders ranks 6th at 2%. Again black children are not hospitalized at the same frequency for mental problems. Instead after birth related hospitalizations, diabetes and sickle cell are the prime causes.

Much of the data that we used to understand mental health issues (i.e., hospital discharge data) was too new to get a sense of whether the adolescent mental health problems were new. However, client count data from the Division of Child Mental Health shows an increase from 1,785 clients in fiscal year 1998 to 1,919 in fiscal year 1999. This number has jumped to 2,264 in the first nine months of fiscal year 2000.

The Department of Education recently conducted the Youth Risk Behavior Survey. Data from this report shows a clear need for mental health intervention. Although the survey does not cover all of the state's adolescents, nor does it take place in all schools, it is broad enough in its coverage to raise concerns. The following statistics are of particular interest:

- Almost 27% of the respondents said that during the past 12 months they felt so sad or hopeless for almost every day for two weeks in a row that they stopped doing usual activities.
- About 17% seriously considered attempting suicide for during the past 12 months.
- 3.7% stated that they had actually attempted suicide.
- 2.4% had to be treated by a doctor or nurse for depression.

There have been some major efforts to address mental health issues through prevention. The Department of Services for Children, Youth, and their Families and 10 of the 20 state's school districts established the K-3 Early Intervention Program. Additional funding was provided for social workers "to reduce classroom disruptions and encourage long-term academic success" and for some programs "to mitigate negative effects of conduct disorder." Unfortunately during the time that this program was evaluated only 11 students actually completed the program. 82% of the cases had closed because of reasons such as the student had moved. 57% of the children in the program had child behavior inventory scores below the conduct disorder intensity threshold score. This score dropped for most of the children who completed the program.

## Gaps in drug and alcohol counseling:

There is also clearly a need for more help for teens who abuse drugs and alcohol. The Youth Risk Behavior Satisfaction survey showed that:

- 23% had at least one drink of alcohol between 40 and 100 or more days.
- 32% had their first drink between 8 or younger and 12 years old.
- 27% had consumed five or more drinks of alcohol in a few hours at least once during the last 30 days.
- 49% had tried marijuana at least once.
- 7% have used cocaine at least once and 1.3% have used it 40 or more times.

- 12% have at least once sniffed glue, breathed the contents of aerosol spray cans or inhaled paints or sprays to get high and .5% have done this 40 or more times.
- 1.3% have tried heroin at least once.

A collaborative effort between Children and Families First, elementary schools and parents, Families and Schools Together (FAST) is an early intervention/prevention program designed to reduce factors associated with school failure, juvenile delinquency and substance abuse in adolescence. Together with nonprofit mental health clinics and assessment clinics for substance abuse, the schools' and parents' participation is geared to result in enhancing family functioning and decreasing child problem behaviors. A total of 845 of the families across the stare completed the process and graduated from FAST. Parents reported a 14% reduction in behavior problems, while teachers reported an 11% reduction

**Nutrition counseling for Adolescents:** The latest YRBS data also provides some understanding of any nutritional problems faced by adolescents. Although there are a small number that have severe nutritional problems, addressing those problems is a critical need. Some of the more serious problems are:

- 11.5% of the respondents stated that during the past 30 days they went without eating for 24 hours or more to loose weight or to keep from gaining weight.
- 4.7% took diet pills, powders or liquids without a doctor's advice during the last 30 days for the purpose of losing weight.
- 3.2% vomited or took laxatives to loose weight or to keep from gaining weight.

On the other hand, 55% exercise to lose weight or to keep from gaining weight. 54.4% participated in physical activities for at least 20 minutes for at least 4 or more days. Following nutritional guidelines also seems to be a problem for adolescents. For instance, only 26.5% reported eating vegetables other than carrots at least 1 time per day during the past 7 days. Only 28.7% had fruit at least once a day during that time period and only 38.2% had fruit juice at least once a day.

One source of nutritional counseling for school students in public schools is the school based health centers. During the fiscal year 1999, there were 2,534 (6% of total) visits where nutrition needs were the primary diagnosis and 3,165 visits where the concern was a secondary diagnosis.

## **Availability of Speciality Care Services**

## 2. Population-Based Services

## **Immunization Program**

The DPH Immunization Program maintains an immunization registry and has made the registry available to providers, school nurses, day care providers, etc via the World Wide Web. State regulations require providers to report all immunizations given to the registry.

The Immunization Program also completed a marketing plan. The purpose was to establish marketing strategies that includes providers and consumers that can impact the immunization coverage in Delaware.

Partnerships with the Delaware Department of Education, the Delaware Office of Child Care Licensing, the Delaware WIC program, the Delaware Adult Flu Coalition and the Delaware Valley Immunization Coalition continued. In each of these instances, to better monitor and improve immunization rates among populations, we enhanced cooperative activities.

School nurses helped assure immunization compliance of all children transferring or entering school for the first time. The program conducted a "Lot Quality" Assurance Assessment (LQA) at the six (6) birthing hospitals in Delaware. The assessment gathered information regarding the screening for hepatitis B in pregnant women during their pregnancy and the percent of infants receiving the birth dose of hepatitis B vaccine before leaving the hospital.

Funding Mechanism: Funding for immunizations comes from state and federal dollars.

Geographic Availability/Distribution: DPH makes an extra effort to reach special and rural populations by providing specific immunization clinics to the Amish population and to the rural residents in southern Sussex County.

# **Lead Poisoning Prevention**

The DPH Office of Lead Poisoning Prevention provides the following services:

- Promotes the testing of all children at 12-months-of age, and repeat testing of those at high-risk until six years of age.
- Provides case management and inspection, for lead hazards, in homes of children with increased blood-lead levels.
- Provides health education programs and materials on the causes and affects of lead poisoning among young children, and how to identify and reduce lead hazards.
- Provides analysis of all results of children tested for lead poisoning to determine which children are at increased risk, and to target prevention programs.
- Distributes lead poisoning prevention information and lead paint test kits in *Growing Together* packets that are distributed to all new mothers in Delaware's maternity hospitals.
- Monitors lead screening of children enrolled in Delaware's health insurance program for uninsured children (CHIPS).
- Provides information on the risk of childhood lead poisoning, state screening requirements and available health resources to Refugees and Foreign Adoption service agencies in Delaware.
- From the DPH Blood Lead Registry, map high risk areas for lead poisoning to the census tract level using Geographic Information System (GIS) geo-coding software.

*Funding Mechanism:* Federal funding sources include Centers for Disease Control, Childhood Lead Poisoning Prevention: Environmental Protection Agency, Office of Pollution, Prevention and Toxics, and the Department of Housing and Urban Development, Lead Hazard Control Program.

Geographic Availability/Distribution: Delaware has a mandatory blood-lead screening law, requiring all children to be blood-lead tested at or around 12 months of age. Children are

identified with elevated blood-lead levels in Delaware by blood-lead testing primarily through their primary health care provider. Screening is also provided through the DPH clinics but since managed care, referrals to DOH have decreased. Ten statewide DuPont Pediatrics sites perform about half of all blood-lead testing that occurs in the state, with DPH providing each DuPont Pediatric site with blood-lead screening supplies and DPH laboratory analysis of their blood-lead specimens, free of charge.

# **Emergency Medical Services for Children (EMSC)**

According to the *Delaware Emergency Medical Services for Children Needs Assessment* (Summer 2003), Delaware's Emergency Medical Services (EMS) program is strong, broad in scope, and well regulated. Children's issues are included, at least to a limited degree, in all aspects of the program because the program addresses the needs of all of the population inclusively. The Delaware Office of EMS is adequately funded, established in law and responsible for developing and overseeing a statewide EMS system. Mechanisms that fund other aspects of the health care system fund EMS, but the EMSC Program is not institutionalized with dedicated funding.

Delaware EMSC has made significant progress in addressing the recommendations of the 1998 needs assessment. This 2003 needs assessment makes 26 recommendations to improve pediatric emergency care in Delaware. The primary areas for improvement include activities to institutionalize EMSC within the state's EMS system, assure pediatric expertise in the overall development and management of the system, and incorporate EMS consumer and family advocates into the managerial structure of the global EMS system.

Overall, the goals of the EMSC program are to:

- Ensure state-of-the-art emergency medical care for children
- Integrate EMSC into existing EMS systems.
- Establish and maintain links with children's primary care providers.
- Provide primary prevention of illness and injury prevention to children and youth.

## **Teen Pregnancy Prevention**

elaware placed population-based efforts in the hands of the "Alliance for Adolescent Pregnancy Prevention" (AAPP). AAPP is a program of Christiana Health Services, which had a contract with DPH, and coordinated statewide adolescent pregnancy prevention initiatives, identified needs, targeted high-risk areas and populations, offered educational workshops and technical support, and also assisted with linking programs and resources.

<u>Local DPH Population Based activities:</u> The following activities were examples of the many activities that took place around this performance measure.

- Information was presented to female teens at local community centers, specifically including pregnancy prevention, abstinence, and birth control methods.
- Field nurses worked with ASK-PAT (Adults Supporting Kids Purity Among Teens) at their spring conference, which was aimed at teens. ASK-PAT is collaborative teen pregnancy abstinence based program between DPH and multiple churches, predominantly African American churches, in Kent and Sussex counties.

- Abstinence education was provided at the middle and high school assemblies by Jeffrey Dean. The program was delivered in some alternative schools and one juvenile detention center.
- Field Staff worked with pregnant women, often teens, to reduce and/or delay the onset of additional pregnancies through counseling, information, and referral to a GYN provider.
- Trainer/Educators worked with a variety of teen related agencies upon request. Topics
  often included Teen Pregnancy Prevention, STD/HIV prevention education, selfesteem, etc.

Funding Mechanism: The AAPP receives funding through the DPH and the federal abstinence education grant.

*Geographic Availability/Distribution:* These programs are statewide.

## **School-Based Health Centers**

School-Based Health Centers (SBHC) operate in 27 out of the 29 public high schools in Kent, Sussex, and New Castle Counties, and are available for any students with parental approval. SBHC's are administered in the DPH's Family Health Services Section (also including Title V) and carried out by medical vendors who are contracted to staff and operate the centers. The SBHC's offer health care services, mental health services and nutrition services to enrolled students. However, they also offer numerous population based services such as Lunch and Learn sessions.

*Funding Mechanism:* SBHC receive most of their funding through state general fund dollars. Once center receives funding from the MCHBG.

*Geographic Availability/Distribution:* SBHC are located throughout the state. One of the schools that does not have a center is in northern New Castle County and the other is in Dover.

## **School Health Programs**

Delaware has an organized, effective system of school nurses managed by the Department of Education (DOE) which places a nurse at every state public school. Other collaborative efforts extend from very young children up to and including high school students. Together DOE and Family Health Services have collaborated in the operation of the scoliosis screening program, the hearing conservation program, and the optometry program. DOE works with DPH's EMSC Program. In addition to Risk Watch, the EMSC program provides training to school nurses on preparing for and managing school emergencies. The DPH and DOE have collaborated to ensure that school based health centers are in any public school that wants one. Together they developed a position statement on School-Based Health Centers, which clarifies the wellness centers' role and scope of services, which can be delivered in the school setting.

There are over 300 full and part time school nurses in Delaware that serve students in public and private schools. The Department of Education and the Division of Public Health have also in partnership, to provide training to the school nurses on bio-terrorism and emergency preparedness.

Funding Mechanism: School programs have a variety of funding sources including state, school district, and federal funds.

*Geographic Availability/Distribution:* In addition to 21 public school systems throughout the state, there are numerous private and parochial schools throughout the state, the majority in New Castle County.

# 6. Children with Special Health Care Needs

## A. Major Health Issues, Gaps, and Disparities

Overall, key informants, through two quality studies, interviewed for the assessment, believed the state's birth to three system which provides services through Child Development Watch (CDW) is an effective delivery system for that age group. CDW service coordination provides a central point of contact for families by linking health care, education, social services, and family support services. Once children turn three, most of the children are served through the educational system where the links to the health care system are not as clear. Most CSHCN are mainstreamed throughout the various school districts. Some are served through the educational system's specialty schools. These schools are also named as a strong resource for families.

Primary care needs are generally taken care of and, particularly with the introduction of duPont Pediatric Clinics, access has improved throughout the state. DuPont CSHCN Clinic and Specialty Clinics have also been noted as being of high quality. (See discussion on providers.) However, for families living in southern Delaware, services are a great distance.

Those interviewed also felt that insurance provided through the state with Medicaid and the Delaware Healthy Children Program was adequate. On the other hand, numerous parents pointed out how difficult it is obtaining approval for some specific services or equipment such as in-home health care assistants, certain wheelchairs, or pull-up diapers. Parents are also more pleased with Medicaid coverage than with that of private managed care companies. In addition, there are other issues of concern such as parent's lack of awareness of available services. (See section on Direct and Enabling Services.)

Most obvious in assessing the CSHCN system is the fact that service delivery is fragmented. After the age of three there is no central contact point. Once a child turns three, service coordination is no longer offered by the state. While some service providers offer case management, the assigned managers generally focus on one area of need instead of a holistic approach to child and family. The provision of service coordination would also help to address other identified needs such as better communication between the public school, primary care physicians and health care insurers; lack of one source of reliable information; and improvement in parents' understanding of health care coverage and SSI. (More details on gaps are found in the sections on Enabling and Infrastructure Building Services.)

# **Service Gaps**

*Transportation:* Community leaders and consumers continue to identify transportation as a major problem in accessing health care throughout the state. Even for Wilmington residents, transportation is cited as a problem with long waits for buses, "non-accommodating schedules", and difficulty in handling several children. Highlights from these discussions are:

- Medicaid requires 48 hours notification.
- Transportation is only provided for the child being treated and one parent making it difficult for a mother with more than one child.
- Even if a parent gets transportation to a doctor's office, she may not be able to get transportation to a pharmacy to pick up a prescription.

Lack of Telephones: Although we do not keep a count of families who do not have a telephone, public health nurses report that many of their clients lack a phone. It is often the case that when a woman calls for an appointment, she cannot make the appointment right away and is told to leave a message. The problem is that the office cannot call back if the patient is calling from a pay phone.

Oral Health: The Division of Public Health, Delaware Health & Social Services contracted with the University of Delaware's Center for Applied Demography and Survey Research to conduct a dental survey which was completed in 1998. One important finding was that Delaware suffers from a serious maldistribution of dentists, which leaves Sussex County with a severe shortage and Kent County far from optimal to meet the needs of the growing population. This finding was based on the industry standard of one FTE dentist for 2000 persons. Most of the shortage in Sussex County appears to be in the western, more rural part, from Bridgeville to Laurel. These are a few highlights from the report: 1) Although 97% of general dentists in New Castle County are accepting new patients, only 84% in Kent and 81% in Sussex are accepting new patients. 2) Wait times for non-emergency patients in Kent County are more than double those for New Castle County patients. 3) Almost 20% of Delaware's dentists will either not be active in five years or are unsure. 4) Younger dentists are more likely to locate in New Castle County. This situation affects all Delawareans particularly those in the lower socioeconomic category. The affect on women, particularly on pregnant women is devastating since lack of dental care can lead to infections that are dangerous to the mother and her fetus.

# **B.** Program Capacity by Pyramid Levels

## 1.) Direct Care Services and Enabling Services

## **Financial Access**

# Impact of Medicaid and Managed Care

State and private health care insurance plays a pivotal role in meeting the needs of all CSHCN. Medicaid's benefits are more generous than the benefits of many private health plans, and include access to basic and ancillary care that are vital for these children.

Medicaid has established standards for access to care and the availability of primary care providers for its Managed Care Organizations (MCOs). In the last Request for Proposal, Medicaid added several requirements for the MCOs to provide adequate access to specialists for children with special health care needs even if it means they need to authorize specialists outside of their contracted provider network. However, most standards are not specific to children with special health care needs such as standards related to waiting time for appointments, service approval time, and travel distance to a provider.

Since the inception of Medicaid Managed Care in Delaware, the Managed Care Organizations (MCOs), have changed twice over four years. Many parents of CSHCN were left to identify a new MCO that provided the same primary care physicians, specialists, care, services, and durable medical equipment. Even if the services were provided by the new MCO, each child had to be reevaluated for their current services. The process of choosing and obtaining a new MCO and retaining current service modalities was challenging to CSHCN and their parents.

Title V used several sources to analyze the impact of Medicaid and overall managed care on children with special health care needs and their families including the Office of CSHCN's survey completed by the University of Delaware.

Medicaid Managed Care Organizations provide networks of care and services for CSHCN including primary, secondary and tertiary care. The designated services and service providers are not always family-centered and community based and those living in the south have long distances to travel to obtain necessary services.

However, the last Title V sponsored survey of parents of CSHCN showed a fairly high level of satisfaction with their children's primary care physician with 84.1% stating that they were very satisfied and 13.3% stating that they were somewhat satisfied. This level of satisfaction was not carried over to satisfaction with their health care plan. 58.8% were very satisfied and 31.6% were somewhat satisfied. In the CAHPS survey (described in the Needs Assessment section on Direct Health Care Services and Enabling Services for Pregnant Women, Mothers, and Infants) which surveyed adults, satisfaction with the health plan was only slightly less than with physicians. The correlation with adult experience and experience with service for their children should be high. However, it seems as if the demands placed on their health plans are greater given the needs of their children.

This survey also identified many of the same problems as the focus groups and Title V sponsored survey respondents identified. The most common complaints include hassles in obtaining needed care, inability to obtain accurate and clear information about available services, and unsatisfactory coordination of services. Families of children whose health conditions are more unstable report less satisfaction with their child's primary health plan and considerable problems coordinating their child's care, accessing needed services, and locating providers with the skills and experience necessary for their children.

Parents need clear information about health plan benefits and ways to access services for their CSHCN. Managed care plans provide Health Benefits Managers to work with parents of CSHCN. However, parents are not always aware of what is available. In addition, the

responsibility for the provision of therapeutic services – mental health, speech, physical and occupational therapy – needs to be clarified for parents because they are often unsure whether these critical services will be provided by their child's health plan or the local school system. They are also unsure as to which health plan, Medicaid or private, will pay for the services. More effective methods to link these systems together and to provide information and support to families are needed. Improved coordination of care and communication among providers of care is essential. For children with complex needs served by many different providers and agencies, greater emphasis on coordinated care is imperative. The more recent needs assessment of CSHCN through Health Systems Research, Inc. is still pending

# **Availability of Prevention and Primary Care Services Shortages of Health Care Providers**

As already described in the Annual Report section, DPH offers diagnostic and short-term treatment services for some special needs for children especially in Kent and Sussex Counties where geographic access is limited.

Specialty Care Physicians: The majority of this state's pediatric specialists are housed in the duPont Hospital for Children. CSHCN and their families who live down state can travel as much as 2 hours or more for a doctor's appointment and then have to go to their local network lab for prescribed blood work and x-rays. A second visit to duPont Hospital may be needed for lab and x-ray follow-up. This process is time consuming and debilitating for a medically fragile child and family.

**Dental Care:** Delaware's lack of dental providers particularly affects children with special health needs. For instance, providers working with children with Cleft Palate have noted that lack of Delaware dentists and orthodontists has been a particular challenge since it is imperative that they receive good dental care to combat the sequelae of their birth defect. At least one parent interviewed during the focus group sessions expressed concerns that most dentists do not want to touch her severely disabled child and she is forced to travel a long distance to du Pont Hospital for needed dental care. The survey of parents of CSHCN showed that while most needed specialty services were provided, a lower proportion of those needing dental services actually received them (77.6%). Since this sample was very small (116 respondents), this problem might not extend to the larger population. However, given Delaware's overall problem providing dental care the results were not surprising.

Physical Therapy, Occupational Therapy, and Speech: School-aged children with special health care needs are often limited to therapeutic interventions in the school setting. Therapies are usually provided in the consultative modality in a group setting by the teacher who consults with the therapists. However, parents have not been included. Therefore, carry over of therapies is a challenge to parents and other caregivers who are not present for the intervention. Parents see a need for additional therapeutic interventions in the home in addition to the functional therapies received in the school. In most cases, they are denied. Parents are not sure if the denial is from the school, primary care physician, and/or their health care insurance. The DuPont Hospital for Children has instituted Specialty Clinics particularly to address the needs of CSHCN in Kent and Sussex Counties. The need for Specialty Clinics outside of the hospital is made known through reviews of clinic appointment books. The hospital has

established standards regarding how long a child should wait for an appointment and how far (there has to be a certain number) a child should travel to an appointment. Once a need is identified a clinic is established (i.e., Cleft Palate Clinic at the Williams State Service Center three times a year and Orthopedic Clinic in Seaford). Plans are underway for a Cardiac Clinic in Seaford and Hematology Clinic somewhere in Sussex County. Clinics are held every month unless the need indicates otherwise. The specialty clinics provide many service providers (MD, RN, Nutritionist, Social Workers, and Dentists) at one location and at the same clinic visit for a child to receive comprehensive services.

**Respite Care:** Respite services are provided in a limited capacity to CSHCN who do not require skilled nursing. It is more difficult to find service providers for technology dependent children than for children with fewer medical needs. Typically, private and public health care insurance does not support respite care. However, there are some available sources of funding. The Division of Mental Retardation (DMR) receives state funds for respite. DMR provides two weeks of respite care to their clients. Children, who demonstrate a 25% cognitive delay, are eligible to receive services through DMR. Parents are given the option to obtain their own respite care provider or the DMR will designate a provider. The United Cerebral Palsy (UCP) offers several state- wide choices of respite care such as, center- based weekend day care; summer day camp; and center -based weekend care. UCP provides services to children with physical disabilities who do not require skilled nursing. The Easter Seal Society provides respite for all children 6 to 14 with a disability. The population served includes families of children with cognitive and physical disabilities (including ventilator dependent). The respite services include weekends and over-night summer camp all in Maryland. The family must pay for the weekend services although there is limited financial assistance from Easter Seals for the summer camp. The state Autistic Program also provides services to families of its students. Families are entitled to 24 hours of monthly respite care, plus an additional 7 days per year. Parents provide some payment and the State Department of Education subsidizes the rest.

In the fall of 2003, The Center for Disabilities Studies at the University of Delaware, leader of the Respite Care Task Force, published a report titled, "Respite Care in Delaware: A Critical Need for Change". One of the key recommendations of this report was to coordinate respite services throughout the state. Soon after the report was released, representatives from Easter Seals Delaware & Maryland's Eastern Shore, a non-profit provider of rehabilitation treatment and support services, established a coalition to work on the respite care issue in the state.

The resulting group, the Delaware Caregivers Support Coalition (DCSC), is chaired by Dr. Tim Brooks of the UD Center for Disabilities Studies and consists of more than 25 members representing consumers, service providers, and state entities. Since the first meeting of the Coalition in January 2004, the group has developed a team charter and vision statement and surveyed respite providers and caregivers to determine the current state of as well as the need for respite.

The needs assessment survey conducted by the DCSC supported previous research, revealing that although opportunities for respite exist, and the residents of Delaware are interested in receiving respite services, caregivers are not always able to obtain these services with ease and

confidence. Based on the results of our research, the DCSC drafted a plan to design and implement a pilot Respite Delivery System to coordinate respite services throughout Delaware.

Based on the recommendations of the Respite Care Task Force for steps in the creation of a respite delivery system, the DCSC conducted statewide needs assessment surveys of respite care providers and caregivers to determine the state of respite and examine the level of unmet need.

To gather information on the respite services currently available to Delawareans, the DCSC sent a brief survey to care providers during the months of July and August 2004. Respondents to the survey were nearly unanimous in their belief that there is a significant need for more respite care in the state of Delaware. The only organization uncertain of the need for respite noted that their clients had never asked for information on the subject.

Most respondents also agreed that funding for respite care is inadequate. Currently, respite care is being funded through private pay, Medicaid, and state funds primarily. Responses suggested that limited funds have resulted in difficulty recruiting and retaining caregivers, ultimately limiting access to services.

Respite services are available to individuals of all ages with disabilities of all types, but survey responses suggest some populations have more opportunities for respite. For instance, it appears that the elderly, people with Alzheimer's, and children with Autism are most likely to receive services, while adults with mental illness and individuals with behavioral disorders are less likely to receive services.

Survey responses indicate that respite services are provided at a wide variety of locations during weekday, evening, and weekend hours. Responses also suggest that planned respite services are far more common than emergency services. It appears, however, that these services all are quite limited. Clients can acquire respite for only a brief period of time due to limited provider resources.

Respite providers offered these key points in the "Comments" sections of the survey:

- There is a need for statewide coordination of respite care.
- There is a complete lack of trained respite workers, with a particular shortage of Certified Nursing Assistants (CNAs) available for respite care that requires a medical component.
- Salaries for respite care workers are much too low with the exception of the Delaware Autistism Program. Low salaries make it difficult to recruit, train, and retain caregivers.
- There is a need to develop a volunteer network of individuals who are willing to provide respite care.
- More in-home respite care is needed. Many clients feel much more comfortable in their home environment.
- Safety and security are major concerns for service providers and caregivers alike, and therefore proper training and background checks are very important.

To develop a better understanding of caregivers' need for and understanding of respite care, the DCSC distributed a survey to nearly 3,000 caregivers across the state of Delaware during July and August 2004. Surveys were distributed by the Alzheimer's Association, Child Mental

Health (CMH), the Delaware Autism Program (DAP), the Division of Developmental Disabilities Services (DDDS), the Division of Services for the Aging and Adults with Physical Disabilities (DSAAPD), the Division of Substance Abuse and Mental Health (DSAMH), Easter Seals Delaware & Maryland's Eastern Shore, and the National Multiple Sclerosis Society. Each organization distributed surveys to a significant portion of their clientele. As of January 2005, a total of 538 surveys were returned. Of these, 282 surveys were completed by caregivers (the remaining 256 were returned by individuals who responded that they were not providing care).

Several common themes emerged during the analysis of the caregiver survey responses. The majority of respondents reported that they provide constant care for a loved one, and an overwhelming number said emotional strain and burnout are their main difficulties in caregiving. Overall, caregivers are concerned for the safety of their loved ones when they are in the care of another. This is of particular concern to the caregivers of people with difficulty communicating and to (the growing number of) aging caregivers; these caregivers worry what will happen to their charges when they are no longer able to provide care. Delawareans are clearly interested in acquiring respite, and hope to identify trustworthy, reliable, and affordable respite care.

The major concerns of caregivers included:

- The safety of their loved ones when they are not present to supervise.
- What will happen to their loved ones when they are no longer able to provide care.
- Finding caring, compassionate caregivers who understand the person as well as the disability, and who will provide dignified care as well as stimulation.
- Finding trustworthy caregivers to provide care in case of emergency/for respite.
- Finding adequate financial resources to fund respite care.

## 2.) Population-Based Services

## **Attorney General's Abuse Intervention Committee**

The Director of CSHCN has been an active participant of the Attorney General' Abuse Intervention Committee with the premise that CSHCN are more vulnerable to child abuse and neglect then the general population. The Attorney General's Abuse Intervention Committee envisions a child protective system where all residents of Delaware recognize and properly respond to child abuse and neglect, where the interventions are appropriate and effective, and child safety and well being are ensured.

The Attorney General's Abuse Intervention Committee mission is to partner child protection professionals (child welfare, law enforcement, medical, mental health, advocacy, legal and related fields) in order to identify opportunities for improvement and develop coordinated multi disciplinary approaches to child abuse and neglect interventions that promote physical and emotional safety.

The AG's AIC has been instrumental in improving the multidisciplinary response to child abuse investigations since 1988. Over the last decade and a half, the AG's AIC has developed Memoranda of Agreement between agencies which outline model practices, has provided expert quality trainings at no to low cost, and has been instrumental in the creation of such

organizations as the Child Death, Near Death and Stillbirth Commission and the Children's Advocacy Center of Delaware. In 2006, the AG's AIC will provide an intensive curriculum on forensic interviewing techniques in conjunction with the American Prosecutors Research Institute.

Although members work in various fields, we have common values. These values guide us in our collaboration:

- 1. Our focus is on child safety and how to limit further trauma to the child.
- 2. We collaborate using a multi-disciplinary approach.
- 3. We openly communicate to promote mutual trust.
- 4. We approach issues in a fair and objective manner that demonstrates cultural sensitivity.
- 5. We are respectful of needs and perspectives of families, agencies and others.
- 6. We promote best practice, utilize problem solving methods, and remove obstacles in the system.
- 7. We fully support and participate in the activities of the committee.
- 8. We utilize our resources in the most efficient way to produce measurable outcomes.

The goals of the Committee are to:

- Develop and maintain membership of committee to ensure multi disciplinary approach
- Increase collaboration
- · Increase awareness and understanding of child abuse and neglect
- Build the professional capacity of those who intervene
- Identify gaps in the system and be solution oriented
- Plan and oversee the Children's Justice Act Grant in accordance with the federal Child Abuse Prevention & Treatment Act
- Explore additional funding opportunities

# 7. Linkages to Promote Provision of Services and Referrals

#### A. State Service Centers

The Division of State Service Centers within Delaware Health and Social Services administers a statewide network of service centers. These centers, 14 in total, serve as multiservice facilities in which various public and private agencies are co-located, with the goal of promoting access to Delaware's health and human service system. The goal is to provide client support services that promote increased accessibility, enhanced service integration and efficient service monitoring. Annually, more than 600,000 visits are made to State Service Centers throughout Delaware. Each service center provides a mix of services appropriate to the communities that it serves. There are over 160 programs and services delivered through state service centers.

The Division of Public Health locates many of its clinics at the centers including several very large operations such as Hudson in Newark, Northeast in Wilmington (New Castle County), Williams in Dover, Milford State Service Center (Kent County), and Bridgeville, Pyle, Laurel, Georgetown and Shipley, all in Sussex County. Refer to map of clinics for more detail. In addition to Public Health, services can include probation and parole, mental health,

social services, and Medicaid.

## B. Christiana Care's Perinatal Behavioral Health Program

All women of child bearing years within the Christiana Care Health System perinatal obstetrical catchment region are eligible to participate in this pilot program aimed at maternal depression. This program spans the continuum of care and coordinates universal screening, education, and treatment efforts as the patient moves through different stages of her life and different parts of the health care system. The goal is to provide seamless care that integrates with pre-existing perinatal and behavioral health pathways. The key components of the program include early identification though universal screening of all pregnant women, assessment/triage to the appropriate level of intervention, and ongoing case management with serial assessments. Services may include social service referrals to community agencies, education and support groups, infant development classes, lactation consultation, perinatal bereavement consultation for previous losses, psychiatric evaluation and counseling, and crisis intervention.

## C. Child Find

Under the Individuals with Disabilities Education Act (IDEA), Delaware has established a Comprehensive Child Find System to locate children with disabilities. The Supporting Documents include the Part C flowchart, which shows the design for the Part C or Birth to Three System. The system was designed in a manner to build upon and expand those programs in place prior to Part C. The flow chart shows how the various referral sources feed into Central Intake. Central intake allows for the tracking and referral linkages for infants and toddlers who are at risk and are not eligible under Part C. Included as an integral part of the Central Intake process is the Home Visiting program.

#### **D.** Medical Home

The Office of Children with Special Health Care Needs in partnership with the Medicaid Office, Family Voices, and the local chapter of the American Academy of Pediatrics is developing a medical home model to meet the care coordination needs of CSHCN. In the medical home model a child's primary care physician will be designated as the medical home to ensure that service delivery is family-centered, community-based, culturally competent, coordinated, comprehensive, cost-effective, and compassionate

## 8. Infrastructure-Building Services

# A. Total Maternal Child Health Population

# 1. Delaware Health Care Commission

The Delaware Health Care Commission is an independent public body that reports directly to the Governor and the General Assembly. It was established by the General Assembly in 1990 to develop a "pathway to basic, affordable health care for all Delawareans". Serving on the Commission are the Secretaries of Finance, Health and Social Services, Children, Youth and their Families, the Insurance Commissioner and six private citizens appointed by the Governor, the Speaker of the House and the President Pro-Tempore of the Senate. The Commission has administrative jurisdiction

over the Delaware Institute of Medical Education and Research, which allows Jefferson Medical College to function as Delaware's medical school and over the Delaware Health Information Network, which promotes an integrated health information network. The Lt. Governor serves as the Chair. While the Director of the Health Systems Development Branch attends meetings and provides public health information as needed, she no longer is providing policy support.

The Health Care Commission has focused on several initiatives designed to increase access to healthcare for uninsured and underserved Delawareans, including the Community Healthcare Access Program, the State Planning Program, and an analysis of the safety net in Delaware. The Health Care Commission also convened a committee around mental health issues and published 'The Committee on Mental Health Issues Final Report.'

#### 2. Delaware Medicaid Office

The Delaware Medicaid Office is administered by the Division of Social Services. Under Delaware's Medicaid program there are two Medicaid Managed Care Organizations (MCOs) and Delaware Healthy Children Program (DHCP), Delaware's SCHIP program. Under the Medicaid managed care plan, Delaware residents chose between the Diamond State Partners, established in 2003 and managed by the state Medicaid office, or Delaware Physicians Care Health Plan, established in 2004 and managed by Schaller Anderson of Delaware, Incorporated. Both Managed Care Organizations offer identical Medicaid benefit packages. DPH works closely with DE Medicaid on a variety of issues, including access to health care coverage and medical homes for all children, including those with special health care needs, and pregnant women, oral health access, prenatal care access, Child Development Watch operations, and early childhood systems development. To date, 139,187 Delaware residents receive Medicaid services and 10,825 children are currently enrolled in the DHCP program.

## 3. Delmarva Health Initiative

Four community partners, including three hospital systems (Beebe Hospital, Bayhealth, and Nanticoke) and the Division of Public Health Office of Primary Care, have joined forces to identify those without a medical home and to provide information to help them to access services. This partnership is responsible for developing and implementing the Rural Health Plan.

## 4. Department of Education (DOE)

The Delaware Health and Social Services, and the Department of Education work collaboratively to develop programs promoting the health of children in Delaware. Examples include the delivery of EPSDT services in the school setting and in providing support for School-Based Health Centers. The Department of Education initiated a Coordinated School Health Coalition in 1999 that includes several commissions or task forces, based upon the CDC *Coordinated School Health Model* which include DPH participation. Currently there are three commissions: Health Education, Health Services, and Physical Education. Future commissions will include Nutrition Services, School Climate, Staff Wellness, and Counseling Services. Thus far standards have been developed for health education that can be used in other

curricula such as reading or social studies. The Coordinated School Health Program Team is composed of a variety of health and education related agencies, private, and public including parents. They recruited school applicants to participate in a needs assessment of health needs in their respective schools. After identifying the specific needs, plans were developed to target those needs. The Department of Education (DOE) has also collaborated with DHSS in development of the Part C early intervention efforts. Staff are also housed and incorporated into the CDW team and serve as liaisons for transition and Individuals with Disabilities Education Act (IDEA B and C) issues. This year the Office of Health Services, DOE, in partnership with the DPH to provide training to school nurses on teen pregnancy prevention, lead poisoning, tuberculosis, immunizations, and public health resources. Delaware has a comprehensive system of school nurses, with one in each school and most private schools. There are over 300 full and part time school nurses in Delaware that serve students in public and private schools. The Department of Education and the Division of Public Health have also in partnership, to provide training to the school nurses on bio-terrorism and emergency preparedness.

#### 5. DOE Head Start Collaboration Office

The DOE-Head Start State Collaboration Office and the Division of Public Health have also partnered under the Healthy Child Care America and ECCS projects to pilot the Partners in Excellence: Promoting Social and Emotional Competencies in Young Children (PIE) project in 15 Head Starts, ECAPs and child care centers statewide. The purpose will be to develop and utilize evidence-based social-emotional classroom strategies to promote resiliency and foster appropriate social-emotional well-being in young children.

# 6. Department of Health and Social Services (DHSS) Division for Aging and Adults with Physical Disabilities

This Division has the lead for Traumatic Brain Injury issues in the state. The CSHCN Director works closely with the Division to ensure that the needs of children are addressed. DPH has also worked with this division on a variety of initiatives for older women. Although the Division for Aging and Adults with Physical Disabilities maintains the lead for the adult TBI issues in the state, the Division of Public Health, CSHCN, is working through a Subcommittee of the Council for Person with Disabilities to address the pediatric TBI/ABI issues. The Division for Aging and Adults with Physical Disabilities has gained approved for a Traumatic Brain Injury Medicaid waiver for the adult population.

# 7. Department of Health and Social Services (DHSS) Division of Social Services Child Care Office

The Division of Social Services, Child Care Office manages the child care services to support families with young children to enable the caretaker to hold a job, obtain training or meet special needs of the child. Child care may also be provided in child abuse cases to help protect the child. The service is available for children from infancy through twelve years of age. DSS determines eligibility based on the need for service and income. The income limit is currently set at 200% of the Federal Poverty

Level (FPL). DPH and DSS-Child Care Office have partnered to ensure that health and safety standards in all licensed child care centers and home statewide are improved through training, technical assistance and regulations. The DSS-Child Care Office is assisting DPH with funding to support the statewide network of child care health consultants in the coming fiscal year.

# 8. DHSS Division of Developmental Disabilities Services (DDDS)

Division of Developmental Disabilities Services (DDDS), DPH collaborates with DDDS on Traumatic Brain Injury issues, respite care, and Child Development Watch operations. The DDDS provides an array of services for individuals with mental retardation and other specific developmental disabilities and their families, who meet eligibility criteria. This agency is currently partnering with DPH and other community partners to pilot universal developmental screening of all children under the age of five.

# 9. DHSS Division of Management Services

This agency provides human resources, budget development, and evaluation services to other DHSS divisions. It also houses the Birth to Three Office, which provides administration for Part C.

#### 10. DHSS Division of Substance Abuse and Mental Health

The Division of Public Health (DPH) works with this agency on women's health issues, planning a women's health conference, and infant mortality issues. There are five objectives related to alcohol and drug use in Healthy Delaware 2010.

#### 11. DHSS Division of State Service Centers

DPH has worked with this agency to improve the following programs designed to assist Delawareans, most in need and link to the appropriate community or state resources:

- The Delaware Helpline provides toll-free information and referral for persons seeking information about public and non-profit services.
- Dental Transportation Services, in cooperation with the Delaware school system, ensures that school-aged eligible low-income children are transported from school to dental clinics located in the state service centers
- Adopt-a-Family is a statewide program that aids families in crisis --- those struggling with illness, homelessness, domestic violence, poverty or unemployment. This year they partnered with DPH to include Back to Sleep and SIDS information to pregnant women and families with children under the age of one. They also partnered with DPH to provide Medicaid/SCHIP information to all families receiving school supplies for their children in the Fall of 2004.
- Kinship Care Program provides assistance for relative caregivers during the 180day transition period when a child first moves into the non-parent caregiver's home. The program assists in meeting the child's immediate needs for clothing, shelter, health, safety, and educational supplies.
- Car seat loaner program provides car seats to needy families.

# 12. DHSS Division for the Visually Impaired

The DPH Child Development Watch works with DVI to provide service coordination for children with visual impairments or who are deaf and blind.

# 13. Federally Qualified Health Centers

The Office of Primary Care is located in the Health Systems Management Section of DPH. The Health Systems Management Director assists as a facilitator to the Federally Qualified Health Centers and coordinates with the Family Health Section Director to ensure a variety of primary and preventive maternal and child health services.

The Office of Primary Care staff continue to work closely to ensure access to healthcare services for uninsured and underserved Delawareans. Delaware has benefited greatly from the President's Initiative to increase access to healthcare services through community health centers. Delaware now has two Federally Qualified Health Centers (FQHCs) in New Castle County (Henrietta Johnson Medical Center), one in Kent County (Delmarva Rural Ministries/Kent Community Health Center), and one in Sussex County (La Red Health Services).

## 14. DHSS Office of Emergency Medical Services

The Office of Emergency Medical Services of the Emergency Medical Services Section, has coordinated with MCH, including CSHCN, regarding issues around emergency preparedness for children and with injury prevention. A Special Needs Alert Program has been activated to link CSHCN with the 911 system and the first responders within their community. There are four objectives related to injury and disability in Healthy Delaware 2010.

## 15. Department of Services for children, Youth, and Their Families

The Department of Services for Children, Youth, and Their Families (DSCYF) was created in 1983 to consolidate child protective (Division of Family Services, DFS), child mental health, and juvenile correction services within a single agency. Family Health Services (FHS) has maintained a cooperative relationship with this agency for joint planning of services. A Memorandum of Understanding (MOU) between the DPH and DFS establishes uniform criteria for responding to reports of abuse and neglect and delineates the responsibilities of DPH and DFS personnel. The MOU addresses the need for ongoing, collaborative training and joint case planning between personnel in each agency. DFS and DPH are co-located at several local sites where direct services are provided. DFS staff is also housed at both sites of Child Development Watch and are fully incorporated into the multidisciplinary assessment team. In addition, DPH has collaborated with the Office of Child Care Licensing to improve the training and support for childcare providers in the areas of health and safety and in the development of the early childhood comprehensive systems planning. The Division of Child Mental Health has a working relationship with School-Based Health Centers, works closely with center coordinators to ensure appropriate referrals and obtain training for staff, and has contributed to the development of the Maternal and Child Health grant.

#### **16. SSDI**

The SSDI program is part of the Health Systems Management Section within Community Health. The SSDI Coordinator serves on the MCH Needs Assessment Steering committee. Other activities, both planned and completed, include the completion of an inventory of resources available in Sussex County and the barriers experienced by the Hispanic population in accessing health care; completion of an oral health care needs assessment of pre-school and elementary school-aged children throughout the state; completion of a Community Health Profile for every community in Delaware and presentation of those profiles to community leaders; and collaboration with the state and community stakeholders in developing strategies for addressing identified needs derived from the MCH needs assessment.

## 17. Women, Infants and Children Program )WIC)

WIC works with the DPH and other agencies to provide services and ensure quality. For instance, WIC was instrumental in the formation of the Delaware Breastfeeding Advisory Board, which now operates under the perinatal Association of Delaware. WIC also works closely with teen pregnancy prevention programs to prevent additional pregnancies, with the Immunization program to esure compliance by their recipients, and with the march of Dimes program to provide information about folic acid.

## B. Pregnant Women, Mothers and Infants

#### 1. Perinatal Board

In November 1995, Governor Carper signed Executive Order Number 37 establishing the Delaware Perinatal Board. Its purpose is to:

- provide oversight for the infant mortality problem
- assess, define and prioritize problems
- assist in the development of an approach
- establish appropriate standards
- assess the state's need for services on a community-by-community basis
- evaluate the effectiveness of initiatives
- coordinate and manage relevant data.

The Perinatal Board has over this past year disbanded while acting as an interim committee to assist with the preparation of legislation for a new *Healthy Mother and Infant Consortium*. The Consortium is the result of a major recommendation of the statewide comprehensive Infant Mortality Task Force.

## 2. Infant Mortality Task Force

The Infant Mortality Task Force was implemented with the following goals to include:

• Defining the infant mortality status of Delaware as compared to the nation and the region.

- Defining the disparities among races related to infant mortality and determining the reasons for the increasing disparity gaps.
- Identifying risk factors and underlying etiologies when possible.
- Reviewing scientific literature with the purpose of determining risk factors for infant mortality and best practices for prevention and intervention.
- Determining and assessing the impact of relevant risk factors.
- Increasing awareness of the scope of the problem among government officials, medical professionals, and the public.
- Improving coordination between and among public and private sector agencies.
- Recommending critical changes to the profile of, operations of, and support of the Delaware Perinatal Board.
- Identifying areas requiring additional research and education.

The results of the "Infant Mortality Task Force" have been finalized with the report and its recommendations forwarded to the Governor. The Infant Mortality Task Force was mandated to develop broad-based recommendations for the reduction of infant mortality in the state of Delaware. The recommendations have been based upon scientific evidence, defined partnerships, expected contributions, timelines, review, and evaluation. These recommendations encompass but are not limited to charges to business, community, education, communities of faith, providers, insurers, and the government. The twenty recommendations include:

- Conduct a comprehensive review of every fetal and infant death in Delaware.
- Create a monitoring system to increase understanding of the risks faced by pregnant mothers in Delaware.
- Establish the Delaware Healthy Mother and Infant Consortium (DHMIC) as successor to the current Perinatal Board.
- Create the Center for Excellence in Maternal and Child Health and Epidemiology within the Division of Public Health.
- Improve access to care for populations disproportionately impacted by infant mortality.
- Provide access to preconception care for all women of childbearing age with history of poor birth outcomes.
- Require that insurers cover services included in standards of care for preconception, prenatal and interconception care.
- Implement a comprehensive (holistic) Family Practice Team Model to provide continuous comprehensive care and comprehensive case management services to pregnant women and their infants up to two years post partum. Services will include comprehensive case management, trained resource mothers, outreach workers, nurses, social workers, and nutritionists.
- Implement federal standards for Culturally and Linguistically Appropriate Services (CLAS)
- Create a cultural competence curriculum for providers.

- Improve comprehensive reproductive health services for all uninsured and underinsured Delawareans up to 650% of poverty.
- Fund an in-depth analysis of programs in Delaware that mitigate infant
  mortality and create and implement an ongoing process for continuous quality
  improvement for services and programs developed to eliminate infant
  mortality.
- Create an epidemiological surveillance system to evaluate and investigate trends and factors underlying infant mortality and disparity.
- Create a linked database system to meet data analysis and program assessment goals and improve health care and services provided to the public.
- Conduct a statewide education campaign on infant mortality targeted at highrisk populations.
- Expand the birth defect registry surveillance and make it proactive by broadening monitoring, early intervention and prevention programs.
- Continue to improve the statewide neonatal transport program.
- Evaluate environmental risk factors for poor birth outcomes.
- Promote oral health care, particularly the prevention and treatment of periodontal disease, as a component of comprehensive perinatal programs.
- Provide an annual report to the governor on current and future factors impacting the availability of obstetrical practitioners. Include recommendations to remedy systems capacity issues.

# 3. Delaware Healthy Mother and Infant Consortium

Pending legislation, HB202 authorizes use of funds to improve maternal and infant health. In addition, the legislation establishes The Delaware Healthy Mother and Infant Consortium (DHMIC) to coordinate efforts to prevent infant mortality and improve the health of pregnant women and infants in the State of Delaware. DHMIC is a network of organizations and individuals that will provide statewide leadership and coordination of efforts to prevent infant mortality and improve the health of pregnant women and infants throughout Delaware. The Consortium's priorities and advocacy agenda shall be initially dictated by the recommendations contained in the report entitled "Reducing Infrant Mortality in Delaware – Recommendations of the Infant Mortality Task Force", released in May 2005. When established, the DHMIC will:

- Provide advice and support to state agencies, hospitals and health care practitioners regarding their roles and reducing infant mortality and improving the health of pregnant women and infants.
- Facilitate collaborative partnerships among public health agencies, hospitals, health care practitioners and all other interested agencies and organizations to carry out recommended infant mortality improvement strategies.
- Recommend standards of care to ensure healthy pregnant women and infants.
- Coordinate efforts to address health disparities related to the health of pregnant women and infants.
- Oversee development and implementation of research activities to better understand causes of infant mortality.

- Coordinate efforts to prevent conditions and behaviors that lead to unhealthy pregnant women and infants.
- Meet semi-annually with the Secretary of Health and Social Services to review progress, priorities, and barriers related to the Consortium's purpose.
- Recommend legislation and regulations that will enhance the health of pregnant women and infants.
- On an annual basis issue a report to the Governor on the status of the health of pregnant women and infants and progress in implementing recommendations of the Infant Mortality Task Force.

# 4. Fetal and Infant Mortality Review Pilot Project

The following information is from the Executive Summary of *The Fetal and Infant Mortality Review (FIMR) in Delaware: Findings from the Pilot Study and Lessons Learned about Implementing a Statewide FIMR, June 2005.* The Fetal and Infant Mortality Review (FIMR) pilot study was born out of an interest to help inform the Infant Mortality Task Force (IMTF) on the potential benefits of locally applying the national FIMR model, a process of reviewing fetal and infant deaths to address gaps in the systems of care that serve women, children and their families. Infant births that resulted in a death at Christiana Care Health System during 2003 were included in the study. The study was limited to one hospital for logistical ease and to facilitate medical record availability. Fifty-six potential infant death cases were identified that met these criteria; eight cases were excluded as being inappropriate for FIMR, and hence the final pilot study sample was comprised of 48 infant deaths occurring to 43 mothers.

Maternal and infant medical records were abstracted on each of the 48 cases, and medical social workers from the Division of Public Health attempted to contact all 43 mothers to obtain a maternal interview. In 18 cases (38% of the pilot sample), maternal interviews were completed. In 21 cases (44%) the mothers refused the interview, and in 9 cases (19%) the mothers could not be located. Medical record information, information from the state service database and the maternal interview, if available, were used to prepare a de-identified summary of each case. One of two multidisciplinary Case Review Team (CRT) panels reviewed each case summary. The CRT panels identified pertinent risk factors for poor pregnancy outcomes in each case, community resources that were available but not used by the mother, and community resources that are not currently available but that may have benefited the mother or infant. From their discussion, the CRT panels derived recommendations to address issues of concern and gaps in systems of care for pregnant women, infants and their families. Five priority issues that were recurring themes upon case review and the resulting recommendations include:

**Issue 1:** Many women presented late to medical attention with advanced preterm labor. Some of these women did not correctly identify earlier signs of preterm labor or chorioamnionitis.

**Recommendation 1**: There is a need for a more comprehensive approach to preterm labor education

**Issue 2:** Many women with risk factors for poor pregnancy outcome, including significant psychosocial needs, experienced a delay in follow-up or inadequate referrals made for public assistance or public health services.

**Recommendation 2**: Facilitate the screening and referral of high-risk pregnant women to increase access to case management, mental healthcare and public assistance programs as appropriate.

**Issue 3:** Many women with infant losses are not accessing bereavement support.

**Recommendation 3**: There is a need for more culturally appropriate and community-based bereavement support services.

**Issue 4:** A notable proportion of the FIMR pilot sample included women who had suboptimal health, significant past obstetric history or poor lifestyle choices at the time of pregnancy.

**Recommendation 4**: There is a need for more culturally appropriate and community-based bereavement support services.

**Issue 5:** Some women in the pilot sample with multiple gestation and/or obesity had inadequate or inappropriate weight gain during pregnancy.

**Recommendation 5**: Nutrition counseling services should be more widely available and reimbursable as a standard of care in pregnancy, especially among high-risk women.

The cases included in the FIMR pilot study sample are not representative of all infant deaths in Delaware. The infant deaths included in the FIMR pilot differed from those deaths excluded in some notable ways, and these differences should be kept in mind when considering the recommendations made. The pilot sample included a higher proportion of cases from suburban New Castle County and fewer cases from Kent and Sussex Counties. A greater proportion of mothers included in the pilot sample had early prenatal care and private health insurance compared to those mothers excluded from the pilot. The infants in the pilot were of younger gestational age and lower birthweight as a group compared to those infants not included in the pilot. The vast majority of infants in the pilot died of complications of prematurity. There were few infants in the pilot who were born at term and lived beyond the neonatal period (28 days).

There were some limitations faced in conducting the FIMR pilot study, and these limitations help inform planning for the long-term implementation of FIMR in Delaware. Recommendations for the major next steps of FIMR implementation include:

- Institutionalize the coordination of FIMR with child death review under the statutory authority of the Child Death, Near Death and Stillbirth Commission. Procedures for FIMR will need to be approved by the Commission.
- Fund staff to implement FIMR including: a FIMR Coordinator, maternal interviewer, an administrative assistant and, for start up, a physician consultant. The maternal interviewer should be a Division of Public Health medical social worker with skills in bereavement counseling.

- Expand the network of community partners working with FIMR to serve on Case Review Teams in Kent and Sussex Counties as well as a team for New Castle County and, if deemed appropriate, the City of Wilmington.
- Set up community action teams to begin reviewing and implementing the recommendations from the pilot study in each of the counties.

The proposed plan for FIMR is a starting point for discussion among the partners and stakeholders in Delaware committed to improving maternal and infant health outcomes. FIMR is a process that is adaptable to local needs and should be reviewed on a regular basis to best serve Delaware's communities.

#### 5. March of Dimes

The Family Health Services Director (Title V) had served on the Program Services Committee of the March of Dimes. The Family Health Services section staff voluntarily serves on various March of Dimes-Delaware Chapter (MOD) committees to improve the health of babies by preventing birth defects and infant mortality. There is current DPH representation on the Program Services, Grants Review and Community Outreach committees. These committees consist of representation from public and private agencies, business leaders, community advocates and family advisors. DPH has provided funding towards the annual prematurity summit which focuses educating the community and medical providers on the specific needs of families with premature or low-birth weight children and development of strategies to reduce the number of premature births. In 2004-2005, DPH also funded a statewide MOD community outreach environmental health initiative providing radon testing kits in the homes of pregnant women and families with infants. Delaware's MOD also is one of 15 chapters to support the NICU Family Support Program which provides direct service and support to families with infants in the NICU of Christiana Care Medical Center. Through our partnership, families are directly linked to DPH programs to assist with transition from hospital to home for the most vulnerable babies prior to discharge. DPH will continue to collaborate with the March of Dimes in a joint effort to increase access to quality prenatal care, reduce the number of premature births and birth defects and improve health outcomes of all children. The MOD staff collaborates and serves on DPH's Infant Mortality Task Force and the Fetal Mortality Review Committee.

This committee which is made up of representatives of many of the agencies described in this application is devoted to developing plans for March of Dimes programs particularly the "Train the Trainer", preconceptional health counseling, application for national program funding, and development of fund raising activities.

#### 6. Perinatal Association

The Perinatal Association merged with Children and Families First; these partners share a similar mission. Children and Families First conducts counseling, foster care, and the Resource Mothers Program. There are nine (9) Resource Mothers, three (3) down state and six (6) upstate. Children and Families First will continue the tradition of targeting women least likely to seek services and the uninsured. The majority of the staff is bilingual. Their role includes, but is not limited to, prenatal, postpartum, and newborn education, transportation to prenatal and pediatric office visits, and assistance with obtaining appropriate resources including insurance, house, and jobs. The merged partnership supports community Resource Mothers. PAD and DPH work as a team on shared client cases and work to provide each client with the most comprehensive care without duplication of activities. Resource mothers are paraprofessionals from the community who identify and assist mothers, their infants, and families with accessing needed resources. They serve as mentors/role models by teaching and demonstrating skills in a variety of areas including menu planning, budgeting, parenting, etc.

#### C. Children and Adolescents

### 1. Head Start and Early Childhood Assistance Program (EAP)

Head Start is administered by seven community-based organizations throughout the state. Early Childhood Assistance Programs (ECAP) are state funded programs administered by the Department of Education and operated by seventeen community based organizations throughout the state, including existing Head Start grantees, school districts, and other early education agencies. Approximately 1,875 children between three and five are served by the traditional Head Start program. Eight hundred fifty (850) four year olds are served by EAP and 40 are served in Migrant Head Start. All programs followed the federal Head Start Performance Standards. The Division of Public Health participates on the Head Start State Collaboration project, which was established to develop state level partnerships for planning and policy development for Head Start eligible children and their families. Priority areas include welfare reform, health access, childcare, social and emotional wellness, disabilities, educational opportunities, volunteerism, literacy, and homelessness. The Head Start State Collaboration Office director serves on the Early Childhood Comprehensive Systems grant (ECCS) steering and executive committees and Healthy Child Care America-Delaware (HCCA-DE) advisory committee. In 2005, HCCA-DE and the Head Start State Collaboration Office have partnered to provide funding and resources for the piloting of Partners In Excellence: Promoting Social & Emotional Competencies in Young Children (PIE) in 15 Head Starts, ECAPS and Child Care Centers statewide. An additional partner is the Devereux Foundation and one of the evaluation measures will utilize the Devereux Early Child Assessment (DECA) tool. This pilot will work with classroom teachers and parents to infuse PIE and DECA strategies into classroom curriculum to identify and minimize challenging behaviors. This pilot will utilize child care health consultants as technical advisors in the classroom setting and will impact over 1500 children, between the ages of 3 to 5. In addition, Child Development Watch staff work with local Head Starts and other

providers on the Sequence in Transition to Education in Public Schools (STEPS) Committee, which concentrates on transition issues for 3 year olds.

# 2. Early Success

The Department of Education's Early Care and Education Office is a key collaborator with the Division of Public Health on the early childhood comprehensive systems effort. Initiated in 1998, Early Success was developed as the state's coordinated plan to address the early childhood issues of children, birth to eight, who received out of home care. The governor established an interagency resource management committee made of the cabinet secretaries from the Department of Health and Social Services, Department of Services to Children, Youth and their Families, Department of Education, Office of Budget, and the Controller General's Office. Additionally, the governor established the Delaware Early Care and Education Council, comprised of private citizens, and the Office of Early Care and Education (OECE) to ensure that Early Success goals and objectives were met. In an effort to provide a comprehensive approach of early childhood services to all families, the ECCS and the OECE, with full support from the Delaware Early Care and Education Council, have partnered to unify Delaware's early childhood initiatives and broaden the initial Early Success plan to include child health, social-emotional development, and expand family engagement domains. This will provide a statewide strategic plan that is comprehensive, coordinated and accessible to all children, birth to five, and their families. It will also enable the Division of Public Health to provide statewide leadership on child health and development issues through multiple public/private collaborations.

#### 3. Child Death Review Commission

The Child Death Review Commission was signed into Delaware law on July 19, 1995. The Commission oversees the work of the two Child Death Review Panels, one for New Castle County and another for Kent and Sussex Counties. The Commission is composed of leaders from state agencies, police, nurses, physicians, attorney general's office, social workers, and child advocates. The Commission has the power to investigate and review the facts and circumstances of all deaths of children under 18, which occur in Delaware. Furthermore, it has the power to administer oaths and compel the attendance of witnesses. Its purpose is not to act as an arm of the police, but to look at systems to determine if the death was preventable. A death is considered preventable if one or more interventions might have averted it. The Commission legislation has been amended to now include child death, near death and stillborn. Efforts are in progress to establish a Fetal and Infant Death Review process in connection with the Child Death Review Commission.

## D. Children with Special Health Care Needs

# 1. State Program Collaboration with Other State Agencies and Private Organizations

The state collaborates with other agencies and organizations in the formulation of coordinated policies, standards, data collection and analysis, financing of services,

and program monitoring to assure comprehensive, coordinated services for CSHCN and their families.

The responsibility for providing direct care and services for children from birth to twenty one years of age falls to more than one agency. Coordination of service delivery within the present system is the key issue. There are numerous providers involved and communication is not always consistent. For children birth to three, the Division of Public Health works closely with several state agencies to ensure collaboration in the continuation of a statewide, comprehensive, coordinated, multidisciplinary, and interagency service delivery system for infants and toddlers with disabilities and/or developmental delays who are eligible under Part C of the Individuals with Disabilities Education Act (IDEA). The Director of CSHCN is responsible for the Part C operations in the Division of Public Health.

The Delaware Coordinating Council for Children with Disabilities (DCCCD or CCCD) has been active as an advisory committee for the CSHCN program. This has increased both the formal and informal interagency collaboration statewide. In addition, the CCCD has received technical assistance from Health Systems Research, Inc. who has initiated a technical assistance plan for the CCCD with a focus on interagency, collaboration, communication, and assessment. A final needs assessment as an outcome of the Technical Assistance Plan is expected to be completed by Health Systems Research, Inc. and will be used as a basis for the Maternal Child Health required needs assessment process for CSHCN.

Numerous representatives from the Division of Public Health participated in Delaware's Continuous Improvement Monitoring Process. The Office of Special Education Programs (OSEP) of the U.S. Department of Education is responsible for assessing the impact and effectiveness of State and Local efforts to implement the mandates of the Individuals with Disabilities Education Act (IDEA) amendments of 1997. "The Continuous Improvement Monitoring Process" is the title given to the process by which impact and effectiveness are determined. As part of this process, Delaware was chosen as one of 16 states to conduct a statewide self-assessment regarding the provision of Early Intervention and Special Education services in the state. The selfassessment was intended to identify both strengths and areas of improvement and compliance issues of the State's Part B and Part C programs for children birth to 21. There were three phases of the self-assessment process, which began in June 2000: 1) Review of the data and the development of the draft self-assessment; 2) The Validation Process; and 3) Review of the public input and finalization of the selfassessment report. Part C strengths were noted in the areas of outreach, collaboration, personnel development, and family satisfaction. Areas of improvement include issues around natural environment, system evaluation, access to services, and tracking. Future plans include utilizing the existing committees to work on areas of improvement while maintaining the current strengths of the system, and utilizing the outcomes when developing a State Improvement Plan. The Director of CSHCN chaired the Quality Management Committee for Child Development Watch. The Quality Management Committee had developed and implemented a system of formal on-site provider monitoring. After this system was established the responsibility for

provider monitoring was assigned to the local entities, Northern and Southern Health Services within the Counties.

Title V provides leadership and some funding for services having to do with children with special health needs in the state. Other private and public agencies also have a lead role affecting this population. Among them are other agencies in DHSS, specifically Medicaid, and the Birth to Three Office in the Division of Management Services, the Division for the Visually Impaired, and the Division of Developmental Disabilities Services. The Division of Child Mental Health, Department of Services for Children, Youth, and Their Families has the primary lead on child mental health and substance abuse issues. The Department of Education ensures that CSHCN are provided with a free appropriate public education. A major private provider is the duPont Hospital for Children, which also administers pediatric clinics. There are also numerous private therapy providers. Goals for children with special health needs cannot be met without the collaboration of these groups. The Delaware Department of Education in collaboration with numerous other agencies and departments, including the DHSS and the DSCYF sponsored annual statewide Early Childhood Summits. The summits have focused on a strategic planning process to address the emotional wellness in young children inclusive of CSHCN. Most recently the Nemours Foundation has established a Division of Preventive Services. One of their three priorities is the emotional health of children including CSHCN. A final consensus report is due year end 2005.

As a result of a needs assessment conducted by the Part C program, a Speech Summit was held to raise the awareness and to formally continue the discussion on the appropriate and effective use of the dwindling of speech and language therapy services in Delaware. The National Early Childhood Technical Assistance Center facilitated the process. A strategic plan was formulated to address the future needs of the CSHCN and their families. That strategic plan is being implemented with new guidelines created and approved under a program called "Enhanced Watch and See". The program addresses speech and language therapy services statewide.

## 2. State Support for Communities

State programs strive to emphasize community systems building through mechanisms such as technical assistance and consultation, education and training, common data protocols, and financial resources for communities engaged in systems development to assure that the unique needs of CSHCN are met.

The State provides support for the development of community-based service programs for CSHCN through; 1) The Medical Home Initiative, 2) the Traumatic Brain Injury Project, 3) the Autism project, and 4) Partners in Policy Making.

*Medical Home:* The Office of Children with Special Health Care Needs (CSHCN) in partnership with the Medicaid Office, the Delaware Chapter of the American Academy of Pediatrics and Family Voices has developed a Medical Home Model to provide care coordination for CSHCN. A Community Access to Child Health

Planning (CATCH) Grant provided funding for training of State and community service providers in the Medical Home Model. In addition, the concept of the medical home has been added to the Medicaid Request for Proposals for managed care organizations. A small CATCH grant was submitted by the Delaware AAP in conjunction with the CSHCN program and was approved. The grant had planned to implement a "certification" process for medical homes focusing on pediatrician and family practice offices. Due to systems issues, the process was never completed. To continue to address the issues, the Medical Home initiative has partnered with the Medical Home subcommittee of the State Early Childhood Comprehensive Systems planning grant. The merging of the two committees has enhanced its membership and its productivity.

Traumatic Brain Injury: The Director of Children with Special Health Care Needs has provided active representation on two statewide initiatives addressing traumatic brain injury. The state support for TBI has shifted systemically to the State Council for Persons with Disabilities. There now is an active a Brain Injury Committee (BIA) of the council, which coordinates the efforts related to TBI/ABI. The Director of CSHCN remains an active member of the committee which addresses both treatment and prevention efforts. The committee includes major participation of parents and young adults with BIA. A major accomplishment of the BIA has been the legislation of TBI as a category for special education services within the Department of Education. The local school districts are now required to report on every child with a diagnosis of TBI which will ultimately effect the range of services afforded to those children and families.

Autism: The Autism Surveillance Project complements the work of the CSHCN Advisory Committee. The data that the project collected and analyzed is used to contribute to the formulation of a state policy on autism, inform discussion of the fiscal resources needed and possible funding mechanisms, facilitate service planning and implementation and allow for the evaluation of the service program. The surveillance project measured the population prevalence of these disorders, breaking down surveillance by subtype, and tracking the prevalence over time. Maryland will compare its population and experience with that of Delaware. The Director of CSHCN is on the Autism Project Advisory Committee. The Maryland/Delaware Autism Surveillance Project expanded into a Center of Excellence called the "Center for Autisms and Developmental Disabilities Epidemiology". Under its monitoring activities, the number of children living in Maryland and Delaware with an ASD is not known. However, we do know that during the 2002-03 school year two hundred seventy eight (278) children ages three to eleven years, in Maryland, were classified as having autism under the Individuals with Disabilities Education Act (IDEA). There are additional children with ASDs who are classified in other disability categories under IDEA or who do not receive special education services. The center used multiple sources to obtain a more accurate estimate of the number of children in the study area with an ASD. The monitoring activities focused on children eight years old.

In a major initiative supported by the Coordinating Council for Children with Disabilities, House Bill 500 was passed in July of 2004. This bill required DHSS/DPH to establish and maintain an Autism Surveillance and Registry Program for the purpose of establishing a central data bank of accurate, precise and current information regarding autism in the State of Delaware. DHSS/DPH was required to adopt regulations requiring health care providers to report of every occurrence of autism in the State of Delaware. The legislation mirrored components of the Birth Defects Regulations to include, "establishing and maintaining a surveillance system and registry". The significant differences include reporting of children to age 18; whereas the Birth Defects is up to age 5. (and requiring both passive and active surveillance and reporting; whereas, the BDR is just passive.) DHSS/DPH is the agency required to adopt regulations requiring health care providers to report of every occurrence of autism in the State of Delaware. Pursuant to 16 Del.C., Sec 223, the Division of Public Health (DPH) has developed the Autism Surveillance and Registration Program Regulations. The Autism Surveillance and Registration Program Regulations will require health care practitioners to report information on children under 18 years of age with autism to a central Autism Registry. Information collected in the Autism Registry will be used to track changes in prevalence of autism over time, to inform the planning of service delivery to children with autism and their families, and to facilitate autism research.

## 3. Coordination of Health Components of Community-Based Systems

Two DPH programs help to coordinate health and community-based systems for CSHCN, Kids Kare, and the Ryan White Program.

Kids Kare: The Division of Public Health provides a multi-disciplinary support program for vulnerable families with children who have been found to be biologically, nutritionally, psychosocially, or environmentally at risk, factors that are highly correlated with a probability of delayed development. A care plan is developed based on the needs of the family determined by risk factors identified at an initial home visit assessment. The families receive support, teaching, and coordination of services in their home from Public Health nurses, social workers, and /or nutritionists. Services are available for low-income families who have Medicaid or who are uninsured. Children up to the age of 21 may be referred but priority is given to those children who are between the ages of birth to six. Children referred to this program may show signs of developmental delay but do not meet the eligibility requirements for the Part C program. An evaluation of the Kids Kare Program is ongoing, with results due in the fall of 2005.

Ryan White HIV program: The Division of Public Health also manages Ryan White Grant funds, which provide case management to a small number of HIV infected children (29 children). The case manager is housed in the A.I.duPont Hospital for Children. Case management is focused on the health care needs of the child to ensure that medical services are provided through an infectious disease specialist, primary care physician, and dentist. HIV positive and negative children are also provided services if they live in a family unit where at least one of the parents is HIV infected.

These may include, case management, food, housing, emergency financial, transportation, and other forms of assistance. There is also an AIDS Medicaid Waiver provided to children who are AIDS diagnosed (total 10 children). The Wavier provides the full range of Delaware Medicaid services along with Waiver specific services of case management, respite, and nutritional supplements. Also, Christiana Care Health Services receives Ryan White Title IV dollars which supplement the Title II activities enhancing the case management and follow up activities with women who are identified as HIV infected or at high risk of infection. There is about a ten percent (10%) increase in persons who access Ryan White services overall, but there is not the same increase related to children. We have not had an infant born HIV infected in the past two years. This is due to mandated counseling and voluntary testing activities at the OB-GYN offices. Also, if a woman is at Labor and Delivery and does not have an HIV result on her chart she will be rapid tested for HIV and if positive started on HIV prophylaxis.

Some coordination is offered for mental health services as described below: *Mental Health:* Children and adolescents under the age of eighteen who receive Medicaid or are uninsured are served by the Division of Child Mental Health Services (DCMHS) in the Department of Services for Children, Youth, and their Families DSCYF DCMHS offers essentially all types of mental health and substance abuse treatment options. These services include: early intervention, crisis services, outpatient, wraparound, intensive outpatient, partial day treatment, day treatment, day hospital, residential treatment, and psychiatric hospital services. In order to promote incorporation of mental health services into primary pediatric care, and to discourage early referrals and institutionalization, private organizations paid for by MCOS furnish 30 units of non-residential mental health services for children. After the 30 units have been exhausted, or on passing a DCMHS assessment for acuity, clients can enter service with DCMHS.

DCMHS also offers extensive services to homeless children. Referrals come from the Division of State Service Centers, Public Health clinics, Head Start, and schools. Most referrals have originated from shelters to the Crisis Services of DCMHS.

The Division also has worked with hospitals to provide on-site emergency room training in appropriate response to mental health emergencies. Specific interrelationships with education include: Membership in the Interagency Collaborative Team (ICT) for funding students with rare and complex conditions, participation in Interagency Coordinating Councils to develop a model of integrated services between mental health and education, provision of mobile crisis services to the school and training in using the crisis services. In addition, the School/Agency Collaboration use a team approach to identify and develop solutions around specific children and families. The initiative calls for school based student support teams that are responsible for case planning and management for service delivery. The team leader serves directly as a liaison to a district-level support team and to the Family Services Cabinet Council agencies. The district level support teams assist the school based teams, state and community agencies in resolving problems, coordinate

training, develop policy to ensure consistency across the district, appoint a single point of contact between the district and the agencies, and assess effectiveness. The Division additionally collaborates with the Department of Education through participation in the State System of Care Team, which is comprised of public and private agencies, families and other advocates.

A Mental Health Shortage Designation Committee has been established in 2005 and includes representatives from the Division of Public Health, the Division of Substance Abuse and Mental Health, the Health Care Commission, and the Division of Child Mental Health. The Committee will be studying the capacity of the systems to address the mental health needs in the state, including children. Projects range from a mental health clinician capacity study to focus groups for both providers and consumers. There are five mental health objectives listed in Healthy Delaware 2010.

**4.** Coordination of Health Services with Other Services at the Community Level Various mechanisms exist in communities across the State for coordination and service integration among programs serving CSHCN, including early intervention and special education, social services, and family support services.

#### Special Education:

About 6 months prior to turning three, the Part C eligible child is referred to a school district Child Find. Referrals with parental permission can come from the CDW service coordinator, primary care physician, relatives, childcare providers, or other professionals. CDW service coordinators work with the school district, parents, and private service providers to establish a transition meeting. The purpose of the transition meeting is to discuss how a child is progressing in his current program. This may include the review of past and present services; discuss the adequacy of those services in meeting the child's needs; explore the possibilities for future services, both short and long term; and determine what if anything needs to be done (site visits, immunizations, etc.) to prepare for preschool.

Delaware carries out Public Law 94-142, Public Law 99-457, and Title 14 of the Delaware Code through its Administrative Manual: Programs for Exceptional Children. This manual states that all eligible students with disabilities are entitled to a free, appropriate public education. A free, appropriate public education is defined as specialized instruction and services, including related services that are designed to enable persons with disabilities to benefit from education. The majority of the schools provide services for children aged three to twenty-one years (3 to 21). However, four categories have been given special status (by legislative mandate) and receive services at birth. "Birth mandate services" are provided from birth to 21 for children who are autistic, deaf-blind, deaf, and blind. Each school district has a Multidisciplinary Team (MDT), which initially determines a child's eligibility for special education services. Based on the results of evaluations, they decide whether the nature and severity of a child's disability meets the criteria established in the Administrative Manual for a handicapping condition that requires special services. Within 30 days of the MDT decision, the school district must schedule a meeting to

develop the child's Individualized Education Program (IEP). The IEP Team determines the program that will meet the child's unique needs. This placement must be based on the child's IEP, and consider the least restrictive environment, age-appropriateness, proximity to the child's home and capability to provide opportunities to be educated with typical children.

In some cases, a child is referred to one of 15 Specialty Schools found throughout the state. As their name denotes, some of the schools target special populations such as, Autistic Program and the Sterck School for the Hearing Impaired. The children who attend the Specialty Schools in most cases have cognitive and physical disabilities and require a host of related services in addition to the educational component. Others are mainstreamed into regular classes. As already described the CSHCN needs assessment-included focus groups of parents of students attending specialty schools. Concerns raised were regarding a limited amount of therapies provided in a group/class room setting as opposed to individual therapy; therapies not being offered in the home with no carry over; and therapies being discontinued due to no progress. Delaware Specialty Schools facilitate parent support groups within their school setting. Principals and/or school nurses invite all parents to attend and participate in the monthly meetings. Parents are encouraged to participate in the development and presentation of the monthly agenda. Monthly meetings provide a forum for parents to verbalize concerns regarding their child's educational needs as well as related services.

# **Family Support:**

Family Forums offer a way to reach out to families statewide, and include monthly meetings throughout the state and address a variety of issues. Typical topics presented this past year include a series of sibling workshops, several sessions on parenting and coping skills, and a session on sensory integration. These Forums are open to families with children birth to kindergarten. Outreach to families is coordinated with the Parent Information Center of Delaware, Delaware's Parent-to-Parent Center. Family Resource Rooms have been set up at each Child Development Watch site as a resource to both staff and families. User-friendly manuals, including listings of books, videos, parent-tips and handouts, are available. The Program also developed an Internet Guide titled, "Children with Special Needs, Internet Guide for Parents and Professionals".

Delawareans with Special Needs: Medicaid Managed Care Panel is a group of parent advocates who meet on a monthly basis with members of the Delaware State Medicaid Office, representatives from the Health Benefits Managers Office, and the two Managed Care Organizations who make up Medicaid's Diamond State Health Plan. Each month a variety of issues are addressed. The meetings are designed to provide a place where people can come to address specific issues or complaints about Delaware's Medicaid Managed Care programs and its providers; give members assistance in learning about the different types of plans available through the

Diamond State Health Plan; and give participants opportunities to learn about Medicaid and keep up with changes.

The Parent Information Center provides state wide services that include; educational advocacy training for parents of children with disabilities; individual technical assistance for families and professionals; information on special education laws and processes; information on the rights and entitlements of persons with disabilities; information on various disabilities; information and training for professionals working with children and youths with disabilities and their families; and disability awareness training and events for schools and community. Resources available at the Center include books, news articles, and videos. The Parent Information Center also provides programs that include individual technical assistance programs; parent educational advocacy programs; and parent-to-parent support.

## E. Major Providers of Health and Health-Related Services

## 1. Christiana Care Health System, Inc.

Christiana Care Health System (CCHS) is the largest provider of health care in the state. It has the only Level 3 neonatal intensive care unit (Christiana Care Special Care Nursery) in the state. The Division of Public Health collaborates with CCHS on many issues for instance; high-risk follow-up for premature infants is provided through a collaborative agreement between the hospitals and CDW. *Christiana Care was the administrator for the Healthy Start project which lost its funding this year. However, the Division continues to work with CCHS to support the Healthy Start consortium.* CCHS also contracts with DPH to administer several School-Based Health Centers. The CCHC's PMRI has been awarded a grant for the last three years by DPH for its Alliance for Adolescent Pregnancy Prevention program. The Chairpersons of the Perinatal Board and its Standards of Care Committee are also CCHS physicians. *Christiana Care also has representation on the Early Childhood Comprehensive Systems Steering Committee*.

## 2. Bayhealth Medical Center

This center incorporates both Kent General in Dover and Milford Memorial Hospital in Sussex County. It is the second largest health care system in the state of Delaware. Bayhealth works on a variety of community initiatives such as the *Central Delaware Community Health Partnership*. Like Christiana Care, it also contracts with DPH to provide oversight for School-Based Health Centers. Bayhealth is also the lead for the Kent Prenatal Task Force, a group of representatives of public and private agencies who seek to improve systems of care in Kent County that impact on early entry into prenatal care.

## 3. DuPont Hospital for Children

The DuPont Hospital for Children, located north of Wilmington, with funding from the Nemours Foundation, serves as a full-service regional pediatric medical center offering a complete range of clinical programs. It has established a system of pediatric clinics throughout the state to provide primary health care for unserved and underserved children. DuPont Pediatric Clinics provide check-ups; physicals; sick visits; vision, hearing, and lead screening; immunizations; referrals to specialists and a 24-hour medical advice hotline for parents.

## 4. Division of Health Prevention Services, Nemours Foundation

The Nemours Foundation established a Division of Health Prevention Services (HPS). The division focuses on child health promotion and disease prevention. The mission of the division is to improve children's health over time through an integrated community-base model that includes:

- Developing and implementing effective prevention programs, building on existing community resources
- Evaluating programs, while also contributing to the national landscape on children's health prevention research.
- Providing business support services and technical assistance to non-profit and health related organizations.

The Division of Public Health Title V has collaborated with HPS on their first three initiatives focused on diabetes, child mental health and obesity.

## 5. Nanticoke Memorial Hospital

Nanticoke Memorial Hospital had worked closely with Delaware Public Health to ensure early entry into prenatal care. A social worker and nutritionists had been housed at the Nanticoke Maternity Center so that they may refer eligible at-risk clients right into Smart Start. Nanticoke Maternity Center closed on 6/30/03. La Red Health Center has absorbed some of the prenatal patients who would have previously used the maternity center. There is no longer social worker or nutrition services housed at Nanticoke. Nanticoke also manages three School-Based Health Centers.

#### 6. Beebe Hospital and Delmarva Rural Ministries

Beebe Hospital and Delmarva Rural Ministries have established a pilot program to provide medical care and links to social services for underserved populations of Sussex County through the MATCH van in targeted areas. *Beebe Medical Center manages three School-Based Health Centers*.

#### 7. St. Francis Hospital

St. Francis Hospital is part of a nation-wide Catholic health system, located in the center of Wilmington. They are involved in community health outreach projects including health fairs and wellness days. They provide Tiny Steps, which is a comprehensive maternal fetal care program, which uses family physicians to provide prenatal, intrapartum, postpartum, and newborn care in Wilmington and Newark.

## 8. American Academy of Pediatrics (AAP)

The DPH has established close partnerships with health professional programs including the Delaware Chapter of the American Academy of pediatrics (AAP). The AAP, Medicaid, and the Family Health Section have participated on the vaccine committee, EPSDT implementation committee, and lead poisoning prevention committee. The AAP has also been involved in the injury prevention efforts of DPH,

Part C planning, the medical home project, and breastfeeding promotion as well as on a scientific committee addressing the problem of infant mortality.

# 9. Selection of State Priority Needs

## A. Determination of Delaware's Priorities

Title V or their match dollars are used to support many of the activities and thus the accomplishments related to both the national and state performance measures. While most of the dollars go to the county health units to provide direct and enabling services, some of the dollars are used to support infrastructure and capacity building and population based services in the central Title V office or those activities performed by the county units. As already described, it is difficult to separate Title V from other DPH initiatives, plans, and programs. Furthermore, it is equally hard to separate out a DPH role, for even when not taking a lead, DPH is usually an active participant.

The Division of Public Health and its collaborating agencies have a long history of supporting interventions that will help us to effectively meet our goals.

Based on the needs assessment, below is the list of identified needs:

- 1. Ensure nutrition services to children and adolescents.
- 2. Improve dental health of children and adolescents.
- 3. Ensure medical home and coordinated services to children with special health needs.
- 4. Improve access to care in Kent and Sussex Counties and for black women throughout the state.
- 5. Reduce teen births.
- 6. Reduce preventable diseases in children and adolescents.
- 7. Reduce preventable injuries to children and adolescents.
- 8. Improve the mental health of children and adolescents through prevention and the assurance of appropriate treatment.
- 9. Reduce black infant mortality.
- 10. Reduce the barriers to delivery of care to pregnant women and women of child bearing years and reduce those risk factors resulting in infant mortality and congenital abnormalities in their infants.

#### B. Delaware's Priorities Related to Pyramid Service Levels

Delaware's Priority Needs are addressed in a variety of programs throughout the state and served to help us to establish performance measures. The following summary outlines some of the needs assessment data, which lead the state to confirm its commitment to the above priorities.

## **Direct Services**

**Ensure nutrition services to children and adolescents.** The latest YRBS showed there are a small number of adolescents that have severe nutritional problems such as bingeing and purging. On the other hand, over half are not eating vegetables on a regular basis or exercising. Although data was difficult to obtain, there do not seem to be enough

nutritionists available to children in any consistent way and only to adolescents in a more limited way through School-Based Health Centers. While children do learn about the basic food groups, this may be an academic exercise and not part of their lifestyle. The newly established Nemours Health and Prevention Services division is making obesity reduction a major initiative. Nemours is working with DPH and other major entities on the issue.

Improve dental health of children and adolescents. The lack of dental services for all poor Delawareans is self-evident. There is a severe shortage of dentists in Sussex County and a less than optimal situation in Kent County and in some sections of the city of Wilmington. Although Medicaid covers dental health for children, not enough dentists will take Medicaid patients. Those dentists that do take Medicaid can not keep up with the demand. The Delaware Healthy Children Program does not cover dental services but if it did, there would not be enough available dentists to provide coverage. By the time, children come to the public health clinics; their teeth have too many cavities for sealants. When adolescents reach adulthood, dental services are even worse in that Medicaid does not pay for services for pregnant women. The Seal- A- Smile program is making inroads for dental care at the elementary school level.

#### **Enabling Services**

Ensure medical home and coordinated services to children with special health needs. It is clear from the ongoing needs assessment that coordination of services for CSHCN over three years is needed. Although there are numerous high quality services in Delaware, delivery is often fragmented and families and other providers are unaware of other services. In addition, a disconnection between education and medical providers has been noted. The issue of the lack of coordination of services when the young adult with special health care needs moves to adult health and social services is even more apparent.

## **Population Based Services**

Improve access to care in Kent and Sussex Counties and for black women throughout the state. Access to care remains a problem in both Kent and Sussex counties and for black women throughout the state. Although Title V has decided to focus on care to all black women as a performance measure, we will continue to carefully review access in the southern part of the state where transportation and cultural barriers are significant. The widest disparity between the two races occurs in Sussex County. There are seven objectives related to access to health care services in Healthy Delaware 2010. In addition, the implementation of the Infant Mortality Task Force recommendations will focus on the access to care issue.

**Reduce teen births.** Although teen birth rates have dropped a little, our rate continues to be one of the highest in the nation. This is another area where there is a large racial disparity between the black teen birth rate and that for whites.

**Reduce preventable diseases in children and adolescents.** *Asthma* may not be very preventable but in some cases, it may be. For instance, roaches, smoking, and kerosene heaters are linked to childhood asthma. Although we do not have prevalence data, we

have hospital discharge data, which shows that asthma is the number one cause of hospitalization for all children 1 to 9. This is also another area where a disparity between whites and blacks is very evident. Proportionately, black children have a higher rate of hospitalization for this disease. For SIDS, the state has adopted case management guidelines. Finally, the state continues to be concerned that children are not getting lead screens, as they should. This problem is particularly noticeable in examining Medicaid data. These are some of the most vulnerable children in the state often living in older homes where lead may be a problem.

Reduce preventable injuries to children and adolescents. The leading cause of death for children 1 to 14 years in the state of Delaware is unintentional injuries. Motor vehicle crashes are the number one leading cause of unintentional injury death in 1-19 year olds. YRBS data also show that the majority of high school students do not always wear a seat belt. Although safety seat use and seat belts have increased, many drivers do not know how to adjust them correctly. Alcohol use by adolescents remains a serious problem. Alcohol use is directly related to injuries to adolescents particularly in motor vehicle accidents but in other injuries as well. The rate of deaths to adolescents in motor vehicle crashes is also increasing at an alarming rate.

#### Infrastructure Building

**Reduce black infant mortality.** The disparity between the rates of black infant deaths and white infant deaths remains an issue. The state's City Match Data Institute team had identified extremely low birth weight and prematurity as the chief direct causes. The state is also considering stress and racism as factors that underlie the problem since both Delaware and national data show that educated black women and those that have accessed care early are still in more danger of losing their infants than white women.

Reduce the barriers to delivery of care to pregnant women and women of child bearing years and reduce those risk factors resulting in infant mortality and congenital abnormalities in their infants. Reducing the barriers has been identified has a high priority to delivery of care. Identified barriers include access to care problems such as cultural, transportation, and insurance issues. Risk factors include lack of early care, substance abuse including tobacco use, lack of good nutrition, being unmarried, giving birth again after less than an 18-month interval, and the age of the mother. There are seven objectives related to Infant health in Healthy Delaware 2010.

Improve the mental health of children and adolescents through prevention and the assurance of appropriate treatment. Mental health issues were raised in many venues: in preparation for the Rural Health Plan, by the Developmental Disabilities Planning Council, by parents in SBHC focus groups, and in review of SBHC data, DCMH client visit, YRBS data, and hospital discharges. After the age of ten, mental health problems were one of the chief causes for hospitalization for white children. While early intervention and prevention have been noted as crucial, there is clearly a gap in providers particularly in southern Delaware. Lack of insurance coverage has been raised as a problem. The Division of Child Mental Health supports services to children who are on Medicaid or uninsured, which does not include the underinsured.

# 10. Summary

Based on the needs assessment, below is the list of identified needs:

- 1.Ensure nutrition services to children and adolescents.
- 2.Improve dental health of children and adolescents.
- 3.Ensure medical home and coordinated services to children with special health needs.
- 4.Improve access to care in Kent and Sussex Counties and for black women throughout the state.
- 5. Reduce teen births.
- 6.Reduce preventable diseases in children and adolescents.
- 7. Reduce preventable injuries to children and adolescents.
- 8.Improve the mental health of children and adolescents through prevention and the assurance of appropriate treatment.
- 9. Reduce black infant mortality.
- 10. Reduce the barriers to delivery of care to pregnant women and women of child bearing years and reduce those risk factors resulting in infant mortality and congenital abnormalities in their infants.

The State's needs assessment process was conducted in a multi-faceted manner. Preventive and primary care services for pregnant women, mothers, and infants, and children were assessed by: 1) reviewing existing reports and surveys; 2) a careful examination of data; and 3) discussions among both professional and community leaders and groups. A Steering Committee was established for the Maternal and Child Health (MCH) component. The needs assessment for MCH had been initiated with the evaluation of Delaware's Smart Start and Kids Kare programs. Even though the needs assessment is required every five years, the assessment has been ongoing and continuous. The major needs assessment process occurred through the State's focus on MCH services as a result of the Infant Mortality Task Force.

For the Children with Special Health Care Needs (CSHCN) component, the Coordinating Council for Children with Disabilities (CCCD) was the advisory group. The Steering Committee for CSHCN is the Coordinating Council for Children for Disabilities consists of over 40 agency representatives and other persons including parents.

The MCH Steering Committee consisted of various members from the Division of Public Health, Medicaid, the Department of Education, the Division of Child Mental Health, WIC, and the Department of Children, Youth and their Families and a parent/consumer. Additionally, after submission of the MCH Block grant the document will be shared with a variety of agencies and councils including the Interagency Coordinating Council, the Interim Committee of the Infant Mortality Task Force (IMTF), the internal Steering Committee for the IMTF and others as appropriate.

The Steering Committee initially reviewed the purpose of having the specific Title V indicators especially related to the National and State Performance measures. The data forms from the MCH Block grant provided a basis to determine progess and trends both positive and negative.

All other relevant data and information was used as back up and explanation for the specific measures. The pyramid of services was introduced to compare what was currently in placeas existing support, resources and activities for direct health services, enabling services, population-based services and infrastructure-building services. The capacity to meet these needs through the MCH Block Grant funding alone was necessarily determined to be insufficient. The real capacity to meet the needs in the pyramid of services is found in the extensive and intensive partnerships and coalitions in Delaware.

Priority areas were selected by a two step process. First, the Coordinating Council for Children with Disabilities conducted a similar review of the pyramid of services with input from topic driven reports on issues related to CSHCN. The CCCD submitted the results of their discussions to the MCH Steering Committee. Three new state performance measures were negotiated at the meetings. The Council composed measures to be specific and time framed, based in hard data consistently collected, and that were connected to Healthy People 2010 objectives. Secondly, the MCH Steering Committee, which included three members of the CCCD, reviewed the three proposed new state performance measures during their needs assessment process. The MCH Steering Committee identified and reviewed the activities that addressed the priority areas including those listed in Figures 4a and 4b of the block grant as related to each state and national performance measure.

Partnership building and collaboration is prominent within Delaware. MCH, with CSHCN collaborates with the following entities: including but not limited to the Delaware Mother and Infant Consortium, Delaware Health Care Commission, Delaware Medicaid Office, Delmarva Health Initiative, Department of Education, Division of Developmental Disabilities, Division of Substance Abuse and Mental Health, Office of Emergency Medical Services for Children, Women, Infants & Children Program, The Fetal & Infant Mortality Review Project, the March of Dimes, and the Coordinating Council for Children with Disabilities.

Discussion of the needs assessment process was held during the MCH Steering Committee meetings over the past five years; during the numerous IMTF meetings and subcommittee meetings from August, 2004 to the current time, and during the Coordinating Council for Children with Disabilities over the past four years. Relevant reports, data sets and literature were reviewed to determine the final priorities. Of note is that three of the ten State Performance Measures were changed in the process.

## 11. Key Reports and Other Resources

## A. Reports

## 1. General

- 2004 Delaware Community Needs Assessment, United Way of Delaware.
- *Kids Count in Delaware Fact Book 2005*, Center for Community Research and Service, College of Human Services, Education and Public Policy, University of Delaware, Newark, DE 19716-7350.
- Delaware Rural Health Plan Progress Report, Delaware Rural Health Initiative, January 2004.
- *Primary Care Physicians in Delaware 2001*, Edward C. Ratledge, Center for Applied Demography & Survey Research, College of Human Services, Education and Public Policy, University of Delaware.
- Dentists in Delaware, 1998, Edward C. Ratledge, Center for Applied Demography & Survey Research, College of Human Services, Education and Public Policy, University of Delaware.
- Health Disparities in Delaware 2004: An Overview, by Eric Jacobson, John Jaeger, and Edward C. Rutledge, Center for Applied Demography & Survey Research Institute for Public administration, College of Human Services, Education, and Public Policy, University of Delaware, with Barbara Gladders, Delaware Health and Social Services, Division of Public Health.
- Delaware's Annual Traffic Statistical Report 2004, Captain Barbara Conley, Director of Traffic Control, and Tammy J. Hyland, Data Analyst, Planning, Delaware State Police
- *Delaware Vital Statistics annual Report 2002*, Winter 2005, Delaware Health and Social Services, Division of Public Health, and Delaware Health Statistics Center.
- Delaware HIV/AIDS EPIDEMIOLOGICAL Profile. 2004

## 2. Pregnant Women, Mothers and Infants

- Reducing Infant Mortality in Delaware, Concept Mapping Summary Report, Concept Systems, Incorporated, November 2004.
- Reducing Infant Mortality in Delaware: The Task Force Report, May 2005.

#### 3. Children and Adolescents

- Building a Comprehensive Early Childhood System in Delaware: Early Childhood Comprehensive Systems (ECCS) Grant Needs Assessment, 2005, Leslie Kosek
- Findings and Recommendations: Delaware Early Childhood Focus Group Study, Health Systems Research, Inc., 2004.
- Delaware Emergency Medical Services for Children Needs Assessment, Summer 2003, Delaware Office of Emergency Medical Services.
- Childhood Injury in Delaware: A Report on Injury-Related Deaths and Hospitalizations Among Children and Adolescents in Delaware 1979 1998, Emergency Medical Services for Children.

- Preventing Child Deaths in the First State Child Death and Stillbirth Commission 2000, 2001 and 2002 Consolidated Annual Report
- A Baseline and Follow-Up Comparison of the Delaware Healthy Children Program, June 2003, College of Human Resources, Education and Public Policy, University of Delaware.

## 4. Children with Special Health Care Needs

- Governor's Advisory Council for Exceptional Citizens: Annual Report, September 2004
- RESPITE CARE IN DELAWARE: A Critical Need for Change, A Report of the Respite Care Task Force of the Family Support Initiative, College for Disabilities Studies, College of Human Services, Education, and Public Policy, University of Delaware, Fall 2003.
- Strategic Plan for Injury Prevention, State of Delaware, Delaware Coalition for Injury Prevention, Delaware Office of Emergency Medical Services, and the Division of Public Health
- *Delawareans Without Health Insurance*, 2004, Edward C. Ratledge, Center for Applied Demography & Survey Research, University of Delaware.
- DCSC Funding Proposal, by the Delaware Caregivers Support Coalition, May11, 2005
- Interagency Resource Management Committee, 2005 Annual Report, Delaware Department of Education
- Delaware Emergency Medical Services Oversight Council 2004 Annual Report, Department of Safety and Homeland Security, Office of Emergency Medical Service

#### **B.** Other References

1. Arias, E., Anderson, R.N., Kung, H.C., Murphy, S.L., & Kochanek, K.D. (2003). Deaths: Final data for 2001. <u>National Vital Statistics Reports</u>, 52(3). Hyattsville, MD: National Center for Health Statistics.

- 4. United States Public Health Service (2001) <u>National Strategy for Suicide Prevention:</u> <u>Goals and Objectives for Action</u>. Washington, DC: PHS.
- 5. Colorado Injury Prevention Program (2004) Suicide Prevention Plan [ttp://www.cdphe.state.co.us/pp/suicide/suicide.pdf].
- 6. U.S. Department of Health & Human Services. (2001). National Strategy for Suicide Prevention: Goals and Objectives for Action. Rockville, MD: U.S. Department of Health & Human Services.

<sup>2.</sup> Brent DA, Pepper JA, Allman CJ, Mortiritz GM, Wartella ME, Zeelenak JP(1991) <u>The presence of and accessibility of firearms in the homes of adolescent suicides: a case-control study.</u> JAMA 266(21): 2989-95.

<sup>3.</sup> Rosenberg ML, Mercy JA, Houck VN. Guns and Adolescent Suicides (editorial). JAMA 266(21): 3030.

- 7. American Association of Suicidology. (2004). "Some Facts About Suicide in the U.S.A." www.suicidology.org.
- 8. U.S. Department of Health & Human Services. (2001). National Strategy for Suicide Prevention: Goals and Objectives for Action. Rockville, MD: U.S. Department of Health & Human Services.
- 9. American Foundations for Suicide Prevention. (2004). <u>Suicide Prevention Strategies</u> [www.afsp.org/index-1.htm].
- 10.Injury Prevention (2004) .Suicide Prevention Strategies
- [http://www.safetylit.org/week/newmenu].
- 11.Centers for Disease Control, Youth Behavior Risk Factor Surveillance System, State Profile [http://apps.nccd.cdc.gov/yrbss].
- 12.WISQARS Injury mortality reports(2001) Centers for Disease Control and Prevention [ttp://webappa.cdc.gov/sasweb/ncipc/mortrate10\_sy.html].
- 13. Tierney, RJ (1998). Comprehensive evaluation for suicide intervention training (dissertation). Calgary, Alberta: University of Calgary.
- 14.Zenere FJ, Lazarus PJ (1997). <u>The Decline of Youth Suicide Behavior in Urban,</u> <u>Multicultural Public School System Following the Introduction of a Suicide Prevention and Intervention Program.</u> Suicide Life Threatening Behavior 27(40: 387-402.
- 15.Shaffer D, Craft L. <u>Methods of Adolescent Suicide Prevention</u>. Journal of Clinical Psychiatry 60[suppl 2] 70-74
- 16.Centers for Disease Control and Prevention. <u>Suicide Prevention Now</u> (2001). Linking Research to Practice. [CD-Rom]. Atlanta, Georgia: NCIPC.
- 17.Suicide Prevention Action Network (SPAN USA) news release, September 9, 2004, <a href="https://www.spanusa.org">www.spanusa.org</a>.
- 18.US Department of Justice-Delaware, <u>Personal communication</u>, 2004.
- 19.Miller M. (2004). <u>Suicide in the United States</u>. <u>Quoted in Lecture notes</u>. John Hopkins school of Public Health. Baltimore Maryland.
- 20.Maris R.W. (1981). <u>Pathways to Suicide. A survey of self destructive behaviors</u>. Reprinted from Maris, Berman, Silverman eds. Comprehensive textbook on Suicidology, 2000.
- 21. Webster D.W (2004). Gun Violence prevention in the USA. Quoted in Lecture notes. John Hopkins University, School of Public health. Summer School.
- 22. Hirofumi, O., Junichi, K., Tomoe, S., Keiko, K (2004). Community-based prevention for suicide in elderly by depression screening and follow-up. Community Mental Health Journal, Vol. 40(3). Pp 249.
- 23.Miller HL, Coombs DW, Leeper JD, Barton SN (1984). An analysis of the effects of suicide prevention facilities on suicide rates in the United States, American Journal of Public Health, 1984; 74(4): 340-3.
- 24.Leisenring D.K (2000). Rural youth suicide prevention: an evaluation Of a community-based intervention project. Dissertation-Abstract International-Section B-Science and Engineering, 2000; 60(7-B): 3570.
- 25.Samar, A (1999). Deliberate self-harm in rural Western Australia: Results from of an intervention study. Australian & New Zealand Journal of Mental Health Nursing; Vol. 8(2), pp 65.

- 26.Campagne, D.M (2004). The Obstetrician and depression during pregnancy. European Journal of Obstetrics and Gynecology & Reproductive Biology, Vol. 116(2).
- 27.Pelkonen, M., Marthunen, M (2003). Child and Adolescent suicide. Epidemiology, Risk Factors, and Approaches to Prevention. Pediatrics Drugs 5(4): 243-265.
- 28.Could, M.S (2001). Youth suicide prevention. Suicide Life Threatening Behavior, 31 Suppl 1:6-31.
- 29.American Academy of Child and Adolescent Psychiatry. Practice parameter for the assessment and treatment of children and adolescents with suicidal behavior. American academy of Child and Adolescent Psychiatry, 40 Suppl. 7:24-51S.
- 30.Poijula, S., Dyregrow, A., Walhberg, K.E et al (2001). Reactions to adolescent suicide and crisis intervention in three secondary schools. International Journal of Emergency Mental health, 3: 97-106.
- 31.Hallfors, D.H et al (2004). Adolescent depression and suicide risk: Association with sex and drug behavior. American Journal of Preventive Medicine. Vol. 27(3), pp 224.
- 32.FDA (2004). Recent changes to the FDA –approved labeling. American Journal of health-System Pharmacy, Vol. 61 (18).
- 34.Shaffer, D., Garland, A., Vieland, V., Underwood, M., Busner, C (1991). The impact of curriculum-based suicide prevention programs for teenagers. Journal of the American Academy of Child Adolescent Psychiatry; 30(4): 588-596.